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**DISABILITY AT THE INTERSECTION OF HISTORY, CULTURE, RELIGION,
GENDER, AND HEALTH**

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The Proof is in the Pudding: Narrative Prosthesis and Pregnancy

Janea Thomason¹

Francis Trollope's *Jessie Phillips* is a blunt and snarky tale with beautiful moments of female friendship right alongside representations of ugly misogyny and brutal infant murder. Along with Trollope's unique style, the progression of narrative events is direct and purposeful. I argue that Trollope employs pregnancy in the novel as a 'narrative prosthesis,' in the same way David T. Mitchell and Sharon L. Snyder argue disability can be used by narratives.² As a narrative prosthesis, pregnancy marks a person as 'abnormal' and as a result, pregnant characters are subjected to the same normalizing process disabled characters often undergo at the conclusion of stories. Trollope makes Jessie's pregnant body a constant reminder of the conflict and then rejects it through the death of Jessie and her baby in order to make way for marriages in the couples around her. Trollope used this narrative pattern to call attention to the unjust cruelty in the way the new bastardy clauses treated pregnant women.³ The use of pregnancy as a narrative prosthesis disrupts the pronatalist myth that pregnancy is the ultimate goal of reproduction, but at the same time, it frames pregnancy as a reproductive pathology, subjecting it to the same medical gaze often turned on disability.

Francis Trollope is not as common a name as other mid-century writers. Tamara S. Wagner has worked to rediscover and reorient Trollope in the literary canon as an author unique in her own right, and Trollope should not be mistaken for her son, Anthony Trollope, who followed her as an author as shares her last name.⁴ Helen Heinemen discusses the blunt approach to social justice issues that typifies Trollope's works. Trollope began her writing career in the 1830s with a scathing travelogue about American culture. She wrote several novels in the American setting, but then turned her interest to reform novels about her home country of England. *Jessie Phillips*, published in 1843, is one such novel.⁵

In *Jessie Phillips*, Trollope sets her sights on the new bastardy clauses in the recent updates to the Poor Laws. These new clauses did not offer women any way to seek support

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² David Mitchell and Sharon Snyder, "Narrative Prosthesis," in *The Disability Studies Reader*, ed. Lennard J. Davis (New York: Routledge, 2016), 224.

³ Helen Heinemen, "Frances Trollope's *Jessie Phillips*: Sexual Politics and the New Poor Law," *International Journal of Women's Studies* 1 (1978): 97.

⁴ Tamara S. Wagner, "Beyond Domestic Manners: Repositioning Frances Trollope in Literary History," *Women's Writing* 18, no. 2 (2011): 155.

⁵ Heinemen, 97.

from the man responsible for their bastard children.⁶ Trollope takes this idea to the logical consequence of men using this to prey on women, and *Jessie Phillips* plays out this supposition. The naïve Jessie is taken advantage of by the upper-class cad Frederic. When Jessie becomes pregnant and Frederic reveals he does not intend to fulfill his promise of marriage, Jessie falls destitute and enters the workhouse. The novel follows the community of women that try to rescue Jessie but to no avail in the face of the law. After Jessie has given birth by herself in a barn, she passes out and does not remember what happens to the baby. Eventually, the baby is found by Frederic and murdered. Jessie stands trial for infanticide but is exonerated only to suddenly die in the courtroom.⁷

I would like to apply the idea of narrative prosthesis to the representation of pregnancy in this novel. David T. Mitchel and Sharon L. Snyder proposed the term “narrative prosthesis” to mark how Western narratives often rely on disability as an integral meaning-making device. I will briefly outline some claims from their theory that frame my use of the term and use *Beauty and the Beast* as an illustration. The first claim is that stories are often started by something being odd and different, and disability is often that difference.⁸ In *Beauty and the Beast*, the story begins with the Beast’s transformation, and the narrative is driven by his need to break the curse.⁹ Second, Mitchel and Snyder argue that disability is used in narratives much like physiognomy, meaning that the outside appearance is used to make an argument about the character of the person.¹⁰ Here Beast’s appearance mirrors his problematic personality.¹¹ The third and most impactful observation, in my opinion, is that when narratives resolve they normalize what was different.¹² They need to return to a cultural homeostasis, which results in the removal of the disability through cure, institutionalization, or death. *Beauty and the Beast* resolves with Adam’s return to humanity and the difference is normalized.¹³

I would like to pull these three features of a narrative prosthesis and show how pregnancy operates in the same way by examining the storyline of *Jessie Phillips*. First, pregnancy is the difference that creates the story, the drama, and drives the narrative. The novel is not a peaceful birth narrative. Instead, Trollope immediately links pregnancy to violence and sucks the reader

6 Ibid, 99.

7 Francis Milton Trollope, *Jessie Phillips: A Tale of the Present Day* (London: Henry Colburn, 1844).

8 Mitchell and Snyder, 226-27.

9 *Beauty and the Beast*. Directed by Bill Condon. Walt Disney Pictures and Mandeville Films, 2017.

10 Mitchell and Snyder, 230.

11 *Beauty and the Beast*.

12 Mitchell and Snyder, 229.

13 *Beauty and the Beast*.

into the characters' lives. Trollope foreshadows the outcome of the story with a reference to Frederic's seduction of Jessie as a ritual sacrifice: "Pretty, innocent, young creature! it was like leading a lamb to be sacrificed amidst the garlanded decorations of a heathen festival."¹⁴ Trollope passes over their sexual intercourse not with the conventions of flowery language or complete obscurity but with a quote from *Hamlet* about murder:¹⁵ "But 'the story is extant, and written in very choice' language of very many lands — so it need not be repeated here" (74).¹⁶ Trollope's use of the *Hamlet* quote draws attention to this not being a mundane birth narrative but a current and tragic one that should be familiar. As we are drawn in to the scandalous relationship and the machinations of Frederic, we anxiously await what will become of Jessie.

One of the ways Mitchel and Snyder argue disability serves the narrative is to reveal the inner workings of a character that would otherwise be hidden from others.¹⁷ Pregnancy can operate narratively the same way. Without a pregnancy, very little would have come from Jessie and Frederic's sexual relationship. She would have been heartbroken and moved on able to hide what had occurred. Instead, a pregnancy acts to make a woman's private sexual life public knowledge. The pregnancy is contrived in order to expose Jessie, which is one way we can see pregnancy operating as a narrative prosthesis instead of just as an event in the narrative. One way it is contrived is because Jessie becomes pregnant after a very short amount of time, and Trollope marks this for readers with dated events in the novel. We do not know the number of sexual interactions that occurred, but we know the span of time in which conception occurred was a matter of months, which makes pregnancy an unlikely outcome. Regardless, a pregnancy occurs, and Jessie's actions are driven by the threat of exposure.¹⁸ Once her pregnancy advances to the point she is altering her clothes to hide it, Trollope describes her as toiling under the "the ceaseless terror of discovery" (179).¹⁹ The risk of exposure and the resulting alienation that will occur prompts Jessie to retreat into the workhouse until her pregnancy is over.

The third feature is the normalization of the narrative that comes with the removal of the difference. The death of the transgressive woman at the end of the narrative is a pattern across long nineteenth-century English novels. The narrative needs to normalize, and there was no or was not shown a way to reconcile the "fallen" woman to normative society. The resolution of

14 Trollope, 41.

15 "Open Source Shakespeare."

16 Trollope, 74.

17 Mitchell and Snyder, 230.

18 Trollope.

19 Ibid, 179.

Jessie Phillips comes with the verdict of Jessie's innocence, yet she still dies suddenly and with no explanation—contrived just like her pregnancy.²⁰ Kristen J. Brandser argues that the courtroom death is symbolic of the lack of Jessie's prospects even as innocent.²¹ Brandser sets up the idea that the lack of narrative options reflects the lack of societal options for transgressive characters. With the death of Jessie's baby and then Jessie, the narrative has normalized by removing what is different and transgressive. At the end, the kind women Martha and Ellen make happy matches.²² In her analysis of marriage plot endings, Ariana Reilly Codr argues that these happy, secondary marriages are one way authors gently let down their readers from the story they are no longer a part of.²³ In the context of viewing the ending as a normalization of difference, these normative relationships replace the taboo relationship in the reader's mind.

Pregnancy's use as a narrative prosthesis mirrors the contemporary medicalization of childbirth. Published around mid-century, the novel sits amidst the long effort by the burgeoning medical field to incorporate reproductive care into its purview. From the movement of doctors into the delivery room in place of midwives and of births from homes and communities into city hospitals to the fact that pregnancy became an area of medical study, reproduction inevitably became pathologized.²⁴ For example, the obstetric anatomy work of John Hunter and William Smellie used dead pregnant bodies as models for the first time. The drawings detailed normal and abnormal pregnancies alike, and their work turned a harsh medical gaze to something that was previously a very private event.²⁵ The medicalization of childbirth frames pregnancy as a reproductive pathology subjecting it to the same medical gaze often turned on disability.

Disability studies offers a new approach to viewing pregnancy in the narrative by drawing attention to the way pregnancy marks the body as 'abnormal' and reduces the perceived humanity of that person. Trollope used pregnancy as a narrative prosthesis to support her argument about the unjust cruelty of the way the new bastardy clauses treated pregnant women. She crafted the narrative to progress and turn out this way to mirror her prediction of how

20 Ibid, 349.

21 Kristen J. Brandser, "In Defense of 'Murderous Mothers': Feminist Jurisprudence in Frances Trollope's *Jessie Phillips*," *Journal of Victorian Culture* 5, no. 2 (2000): 201.

22 Trollope, 350-51.

23 Ariana Reilly Codr, "After Ever After: The Marriage Plot's Farewell to Its Reader," *New Literary History* 50 (2019): 198.

24 *Nursing & Midwifery in Britain since 1700*, ed. Anne Borsay and Billie Hunter. (London: Bloomsbury, 2012).

25 Lyle Massey, "Pregnancy and Pathology: Picturing Childbirth in Eighteenth-Century Obstetric Atlases," *Art Bulletin* 87, no. 1 (2005): 73-4.

pregnancy would affect women under the new law. Her use of pregnancy as a narrative prosthesis reveals how pregnancy would strip women of agency and choices in the current system. Once Jessie is pregnant, there are fewer options available for her, and every effort she makes to improve her situation is thwarted by the law. Heinemen points out that *Jessie Phillips* is the only novel we know to address the unpopular bastardy clauses in the new Poor Laws, and she attributes the overturning of the clauses to the attention drawn by the novel.²⁶

We need to link *Jessie Phillips* and other similar nineteenth-century novels and their conversations to current reproductive rhetoric. The fight for reproductive rights and freedoms has been going on as long as those freedoms have been challenged. Brandser concludes that the bastardy clauses show “the thematic importance of controlling women’s sexuality and reproduction, with the protection of infants being an inconsequential subplot.”²⁷ The same could be said for some current reproductive laws. This is not a new conversation, and, it is not over, either. Current anti-choice, pronatalist rhetoric employs the idea of devaluing the life of the pregnant person, and the consequences of the legislation that follows is often the same as in *Jessie Phillips*—death. We need to link these stories to create the kind of fervor that resulted in overturning unjust nineteenth-century laws in order to address our own.

26 Heinemen, 101-2.

27 Brandser, 185.

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Enigmatic, Tragic, Crip; or, Crip Time in Sophocles's *Oedipus* and Aristotle's *Poetics*

Maxwell Gray¹

Tragedy represents a classical literary genre the field of disability studies often prefers not to approach too closely, lest disability also be called a tragedy by association. People with disabilities prefer not to imagine their lives and bodyminds as tragedies, and I am no exception. But at the same time, I also cannot help thinking disability often represents real tragedy in people's lives, at least disability that takes place in what we imagine the "prime of life," as was my own personal experience of impairment and disability in my mid-twenties. Of course, one of the lessons disability studies teaches us is to reimagine normative ableist ideas and timelines of life, health and ability. For example, my own personal healthcare research taught me what we imagine the "prime of life" is in fact a period of life especially "prime" for disability, when many physical and mental disabilities first begin to appear and develop in early adulthood.

In this essay, I read classical literary and philosophical texts as theoretical exercises of this kind of reimagination of disability. But whereas disability studies often organizes its thinking around forms of disability that appear in childhood, my own thinking is primarily organized around my personal experience of disability that appears in early adulthood, when it's maybe least expected and most difficult to comprehend; or, in a word, tragic. I turn to the literary genre of classical Greek tragedy to identify and think about/with more enigmatic and tragic forms of disability and crip temporality. In particular, I read Sophocles's classic tragedy *Oedipus* and Aristotle's foundational interpretation of the tragedy's plot in his *Poetics*, and I do so together with theories of crip time from disability studies and crip theory.

If disability is sometimes a tragedy, then it is one disability studies reminds us we may all experience at/on some "stage" of our lives. With this vision in mind, of disability always "in the wings," Alison Kafer defines crip time this way:

Crip time is flex time not just expanded but exploded; it requires reimagining our notions of what can and should happen in time, or recognizing how expectations of 'how long things take' are based on very particular minds and bodies. We can then understand the flexibility of crip time as being not only an accommodation to those who need 'more' time but also, and perhaps especially, a challenge to normative and normalizing expectations of pace and scheduling. Rather than bend

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disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds.²

Like many of us—some of whom claim disability identities, and others of whom do not—I have had to reimagine what I can accomplish and/or hold myself responsible for in a single academic semester or year, and redesign my days, weeks and plans to incorporate periods of rest, recovery and relapse that are specific to my bodymind. I have also experienced intense feelings of relief at the recognition and acceptance of real limits of my abilities to keep up with the speed and performance of academic work and life. But at the same time, I also believe if crip time bends our clocks, then crip time remains fundamentally out of our control and beyond our abilities to imagine and design for in our lives and communities. My own often painful experience of crip time is it can never be completely anticipated or planned (to be flexible) for in advance of its own happenstance arrivals. I would say crip time represents a specifically “chronic” interruption of normative ableist expectations of ability and rhythm. Here I am trying to push Kafer’s often-cited definition to also include more uncomfortable and indeed fatiguing forms of crip time. The flexibility of crip time is often exciting and empowering, but it can also often bend us to or past our breaking points.

My intervention is aligned with Susan Wendell and individuals she calls the “unhealthy disabled,” as well as Margaret Price and what she identifies as the “badness” of pain for disability studies and identity politics.³ Both Wendell and Price challenge disability scholars and activists to also do justice to medical and other physical hardships and discomforts of disabled bodymind experiences that may not sit especially well in dominant social and cultural models of disability in disability studies scholarship and identity politics activism. My intervention is also very closely aligned with Ellen Samuels where she reads crip time as a scene often of grief and loneliness. Among other words for it, she identifies crip time as “broken time.” She writes, “It requires us to break in our bodies and minds to new rhythms, new patterns of thinking and feeling and moving through the world. It forces us to take breaks, even when we don’t want to, even when we want to keep going, to move ahead. It insists that we listen to our bodyminds *so* closely, *so* attentively, in a culture that tells us to divide the two and push the body away from us while also pushing it beyond its limits. Crip time means listening to the

² Alison Kafer, *Feminist, Queer, Crip* (Indiana University Press, 2013), 27.

³ Susan Wendell, “Unhealthy Disabled: Treating Chronic Illnesses as Disabilities,” *Hypatia* 16, no. 4 (October 1, 2001): 17–33; Margaret Price, “The Bodymind Problem and the Possibilities of Pain,” *Hypatia* 30, no. 1 (January 1, 2015): 268–84.

broken language of our bodies, translating them, honoring their words.”⁴ Crip time may always be broken time, and indeed often breaks disabled, crip and other queer bodyminds into figurative and/or literal pieces, located at crowded intersections of history, culture, and physical and mental pain.

One way I offer here we can faithfully translate and do justice to the broken, fragmentary poetics of disabled bodyminds is allowing ourselves the complex pleasures of sitting down and staying awhile with the classic tragic emotions of pity and fear. In the *Poetics*, these are the two emotions Aristotle identifies as the essence of classical Greek tragedy (II.6).⁵ His teacher Plato says emotions like these are dangerous because they threaten to overwhelm and obstruct the faculties of the rational mind. However, Aristotle argues tragedy in fact effects a strategic intellectual purification and/or refinement of these emotions, and of course he takes Sophocles’s *Oedipus* as his prime example of this so-called “tragic effect” (*catharsis*). Contra Plato, Aristotle and Sophocles have things to teach and/or remind us of about disability, physical and mental health, and enigmatic and tragic forms of crip temporality.

At the same time, maybe the most famous lines of the Oedipus myth are not actually lines from Sophocles’s tragedy. I am thinking of the famous riddle or enigma of the Sphinx, whom Oedipus finds laying siege to the city of Thebes when he arrives there traveling from Delphi, and in return for solving whose riddle he frees the city and wins the crown of the king and marriage to the queen Jocasta. The standard classical version of the riddle is preserved by Athenaeus: “There walks on land a creature of two feet, of four feet, and of three; it has one voice, but, sole among animals that grow on land or in the sky or beneath the sea, it can change its nature; nay, when it walks propped on most feet, then is the speed of its limbs less than it has ever been before.”⁶ Meanwhile, the standard classical version of the riddle’s solution is preserved by Apollodorus: “Oedipus found the solution, declaring that the riddle of the Sphinx referred to man; for as a babe he is four-footed, going on four limbs, as an adult he is two-footed, and as an old man he gets besides a third support in a staff.”⁷

⁴ Ellen Samuels, “Six Ways of Looking at Crip Time,” *Disability Studies Quarterly* 37, no. 3 (Summer 2017).

⁵ Aristotle, *Poetics*, translated by Anthony Kenny (Oxford University Press, 2013); Aristotle, *Poetics*, translated by Malcolm Heath (Penguin Books, 1996).

⁶ Athenaeus, *The Learned Banqueter*, ed. and trans. S. Douglas Olson (Harvard University Press, 2006-2012), X.456b.

⁷ Apollodorus, *The Library*, ed. and trans. James George Frazer (Harvard University Press, 1970), III.7.

Henri-Jacques Stiker interprets the riddle as a reflection of the hero's childhood deformity.⁸ Similarly, David Mitchell reads the riddle as the beginning of a story about disability and prosthesis: the three legs being the feet and cane of a person with a physical impairment.⁹ Meanwhile, French classicist Jean-Pierre Vernant identifies the riddle as a premonition of the hero's own trans-generational status as husband of his own mother, and father of his own brothers and sisters.¹⁰ However, a specific crip temporality of the riddle has gone largely unnoticed by scholars and critics of the myth, and indeed also by the hero himself.

On the one hand, Oedipus's explanation of the riddle's solution traces a normative ableist timeline of three progressive stages of human life and mobility: humans begin their lives as children and crawl on all fours, grow up into adulthood and walk upright on two feet, and then at the end of their lives enter into old age and walk with the help of a cane. The timeline ties progressive stages of life to their own specific normative ableist modes of mobility. It represents a prime example of what Kafer calls "normative and normalizing expectations of pace and scheduling."¹¹ But on the other hand, the riddle itself is far less invested in the distinction and order of progressive periods of life than it is in the different modes of mobility themselves. Part of the riddle's difficulty is in fact its interest in a grammatical temporal suspension and collapse of these different modes of mobility. The riddle challenges its listeners to imagine they may themselves at any time always change the number of "feet" on which they walk. Indeed, the last line of the riddle imagines a human who graduates from crawling on their hands and knees to walking upright on two and then three "feet," but then returns again to this "slow-motion" mode of mobility sometime later in life. The riddle seems to say the arc of one's life is in fact often not always exactly a smooth and one-way street from crawling on all fours to walking on two feet to walking with a cane or other prosthesis. Oedipus's explanation of the riddle's solution entirely glosses over and represents an ableist normalization of the riddle's "enigmatic" crip temporality.

So, yes, Oedipus arrives at the riddle's correct solution, but seemingly not for the exact correct reasons. If we want to give him a little more credit, then key to his solution of the riddle may be his own personal experience of physical injury and impairment, as variously suggested by Stiker and Mitchell. But in Sophocles's tragedy, Oedipus insists to Tiresias and Creon he

⁸ Henri-Jacques Stiker, *A History of Disability* (University of Michigan Press, 1999), 52.

⁹ David T. Mitchell and Sharon L. Snyder, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (University of Michigan Press, 2000), 61.

¹⁰ Jean Pierre Vernant and Pierre Vidal-Naquet, *Myth and Tragedy in Ancient Greece* (Zone Books, 1988), 138.

¹¹ Kafer, 27.

solved the Sphinx's riddle by his intelligence (*sophos*) alone—a key word in the Greek text.¹² At the same time, Sophocles's tragedy tells a very different story: the hero enters onstage at the beginning of the tragedy walking on two feet, and exits blind at the tragedy's end walking on three or more "feet" with the help of (human) prosthesis. Between the hero's entrance and exit, Sophocles's *Oedipus* dramatically performs an ironic unpredictability of disability that exceeds and confounds the hero's own intelligence of exactly how many "feet" he himself will walk on at day's end. (The critical unit of time in Greek tragedy is always a single day.) Indeed at the end of the tragedy, the chorus's last lines juxtapose the hero's solution of the Sphinx's riddle and his tragic fall: "People of Thebes, my countrymen, look at Oedipus. / He solved the famous riddle with his brilliance, / he rose to power, a man beyond all power. / Who could behold his greatness without envy? / Now what a black sea of terror has overwhelmed him. / Now as we keep our watch and wait the final day, / count no man happy till he dies, free of pain at last."¹³

These lines do two things. First, they compare and contrast the heights and depths of human intelligence and ignorance. They recall the "brilliance" of the hero and his solution of the Sphinx's riddle of humanity (*anthrōpos*), right before they end the tragedy with a statement of profound ignorance of human happiness. The last line represents an exemplary expression of the common Greek elegiac and tragic trope: "count no man happy till he dies, free of pain at last." Francis Fergusson puts it this way: "For the particular virtue of Sophocles' presentation of the myth is that it preserves the ultimate mystery by focusing upon the tragic human at a level beneath, or prior to any rationalization whatsoever."¹⁴ Contra Bernard Knox's classic reading of the play, Sophocles's tragedy represents a deeply religious rebuttal of the intelligence (*sophos*) the hero preaches. Second, these lines effect a turn away from the hero and toward the audience, implicating them and their own bodyminds in the hero's tragic fall. They specifically identify human happiness with freedom from pain, while at the same time placing no faith in the endurance of this freedom. Robert Cohen writes of the end of the tragedy: "Man's feebleness, ruthlessly demonstrated, is crushingly and unambiguously confirmed."¹⁵ The tragedy of Oedipus in the last lines of Sophocles's drama is this "one-two punch" of tragic human ignorance and "feebleness."

¹² Sophocles, *Oedipus Rex*, ed. R. D. Dawe (Cambridge University Press, 2006).

¹³ Sophocles, *The Three Theban Plays*, translated by Robert Fagles, and introductions and notes by Bernard Knox (Penguin Books, 1984), 1678-84.

¹⁴ Sophocles, Luci Berkowitz, and Theodore F. Brunner, *Oedipus Tyrannus, a Norton Critical Edition* (W.W. Norton and Company, 1970), 185.

¹⁵ Sophocles, Berkowitz, and Brunner, 181.

Indeed, Cohen's "crip" choice of words here invites further comparison of the last line of Sophocles's tragedy and the common disability studies dictum that says impairment and disability are "only a matter of time." Both lines represent an ironic hold of one's breath that anyone can live life in the absence of human pain and disability. Instead, they both withhold judgment of anyone's simple happiness or able-bodiedness till a later time, and imagine the two are always only temporary human phenomena. But whereas the disability studies dictum identifies itself as a special knowledge of life and disability, the last line of Sophocles's tragedy imagines itself as an existential ignorance of crip futures and what disabilities they may bring—"four-footedness?"—although it does have its safe bets of pain and suffering. Werner Jaeger writes, "To know oneself is thus for Sophocles to know man's powerlessness; but it is also to know the indestructible and conquering majesty of suffering humanity."¹⁶ The tragedy's end enacts this sublime aestheticization of humanity's horrific ignorance of its own disability, pain and suffering and ironic enigmas of crip temporality; or, in the words of the tragedy's last choral ode: "You are my great example, you, your life / your destiny, Oedipus, man of misery— / I count no man blest."¹⁷ Indeed, H. D. F. Kitto reminds us: "If we contemplate, as we should, the whole play and all its aspects, we see that Oedipus is not a special case, except in the degree to which he suffers; he is, as the Chorus says, typical; what has happened to him is part of the whole web of human life."¹⁸

In this reading of the tragedy's human significance, disability represents a singular site of tragic reversal and recognition. In the *Poetics*, Aristotle identifies "reversal" and "recognition" as the two narrative forms tragedy uses to produce its "tragic effect" of intellectual-emotional purification (II.6). He calls reversal a "change of direction in the course of events," and recognition a "change from ignorance to knowledge."¹⁹ He identifies the best kind of tragic narrative as the coincidence of both forms, and points to Sophocles's classic tragedy as the prime example of this overlap. Here is the critical moment in Sophocles's drama: "Oh god— / all come true, all burst to light! / O light—now let me look my last on you! / I stand revealed at last— / cursed in my birth, cursed in marriage, / cursed in the lives I cut down with these hands!"²⁰ In this moment, the hero experiences a traumatic recognition of his own horrible identity that represents its own tragic reversal of his fortunes from husband and father to son

¹⁶ Ibid, 134.

¹⁷ Sophocles, *The Three Theban Plays*, 1318-20.

¹⁸ H. D. F. Kitto, *Greek Tragedy: A Literary Study* (Doubleday Anchor Books, 1950), 145.

¹⁹ Aristotle, 30.

²⁰ Sophocles, *The Three Theban Plays*, 1305-10.

and sibling, as well as from sacred king to sacrificial exile. Here I want to use these critical terms to analyze the hero's blindness and disability at the end of Sophocles's tragedy. At the same time, I also want to inflect Aristotelian recognition with some of what disability studies teaches us about disability identity and identification.

Tobin Siebers interprets scenes of overt verbal and visual disability self-identification as representations of different ways disability is performed, lived and viewed in public spaces. For example, someone who uses a guide dog may also use a cane to more overtly visually identify and represent their disability to otherwise misunderstanding business owners; or, the same person may also sit down on a bus and begin reading a book, thereby disrupting ableist-essentialist assumptions of what exactly blindness means in different contexts.²¹ Meanwhile, Ellen Samuels describes personal struggles to gain recognition of invisible disability identities that resonate with the complicated scenes and characters examined by Siebers. She writes, "In the absence of recognized nonverbal signs, we often resort to the 'less dignified' response of claiming identity through speech. The complex longing, fear of disbelief, and internal dissonance caused by coming out in this form resound through the narratives of all people who pass by default. Passing subjects must cope with a variety of external social contexts, few of which welcome or acknowledge spontaneous declarations of invisible identity."²² If rights and access require successful disability recognition, and indeed they do, then recognition represents a critically charged social and psychological landscape for thinking impairment and disability identity.

Following his traumatic self-recognition and tragic reversal of fortunes, Oedipus immediately exits the stage. When he returns back onstage at the tragedy's end, the hero has blinded himself by his own hands. He cries out: "Dark, horror of darkness / my darkness, drowning, swirling around me / crashing wave on wave—unspeakable, irresistible / headwind, fatal harbor! Oh again, / the misery, all at once, over and over / the stabbing daggers, stab of memory / raking me insane."²³ The language of these lines represents the tragedy's dramatic and rhetorical collapse of the hero's tragic reversal and recognition and physical blindness ("horror of darkness"). The classic allegorical reading of the scene interprets the hero's literal blindness as a material manifestation of his metaphorical "vision" (knowledge) of his tragic

²¹ Tobin Siebers, "Disability as Masquerade," *Literature and Medicine* 23, no. 1 (2004): 1–22, 9–11.

²² Ellen Samuels, "My Body, My Closet," *GLQ: A Journal of Lesbian & Gay Studies* 9, no. 1/2 (January 2003): 233–255, 241.

²³ Sophocles, *The Three Theban Plays*, 1450–56.

birth and marriage. For example, Charles Segal writes, “By the end of the play, Oedipus exchanges his external, physical vision for a blindness that brings with it, at last, freedom from illusion and a clear sight of the truth about himself.”²⁴ In Aristotelian terminology, the hero’s blindness reflects his traumatic recognition of his horrible identity and marriage. At the same time, an Aristotelian interpretation of the end of the tragedy can also help us understand Sophocles’s *Oedipus* as an essentially human drama of shared disability identity and problems of disability recognition internalized in the psyche of its tragic hero.

The hero’s self-blinding also represents its own desperate, performative act of recognition of the true significance of the “enigmatic” crip temporality of the Sphinx’s original riddle. Indeed it tragically enacts a postlapsarian, prophetic recognition and fulfilled metaphorical “vision” of disability’s ultimately mysterious revelation. In the tragedy’s last scene, the hero’s own ironic change of disability fortunes coincides with this belated, tragic recognition of humanity’s existential disability identity and crip timeliness. He says to the chorus: “Now I’ve exposed my guilt, horrendous guilt, / could I train a level glance on you, my countrymen? / Impossible! Now, if I could just block off my ears, / the springs of hearing, I would stop at nothing— / I’d wall up my loathsome body like a prison, / blind to the sound of life, not just the sight. / Oblivion—what a blessing . . . / for the mind to dwell a world away from pain.”²⁵ Rather than a simple lesson about ableist-essentialist sensory deprivation, blindness seems to effect in Oedipus a more nuanced recognition and uncomfortable acceptance of the impossibility of walling off one’s bodymind and self from the outside world and its different bodily sensations and sufferings. “Oblivion” may seem like a blessing, but it is one that always remains beyond the possibilities of human life. At the end of the tragedy, the hero’s own crip-temporal disability recognition represents this difficult knowledge of existential human embodiment, disability and suffering.

Indeed, this is the message of the emotional climax of the tragedy, where Oedipus speaks to his daughters Antigone and Ismene. He says to them: “You, little ones, if you were old enough / to understand, there is much I’d tell you. / Now, as it is, I’d have you say a prayer. / Pray for life, my children, / live where you are free to grow and season. / Pray god you find a better life than mine, / the father who begot you.”²⁶ Scholars and editors dispute the authenticity

²⁴ Sophocles, *The Theban Plays*, trans. David Grene, and introduction by Charles Segal (Alfred A. Knopf, 1994), xxiii.

²⁵ Sophocles, *The Three Theban Plays*, 1516-23.

²⁶ *Ibid.*, 1655-61.

of this scene, but these lines seem the essence of the human tragedy of the drama. In the words of Kitto's description of the scene: "Such is life, such are the gods. The innocent suffer with the guilty."²⁷ The scene dramatically represents the problem of imagining disability futures discussed by Kafer. She writes, "The task, then, is not so much to refuse the future as to reimagine disability and disability futures otherwise, as part of other, alternative temporalities that do not cast disabled people out of time, as the sign of the future of no future."²⁸ If Sophocles's tragic hero has a single "tragic flaw" (*hamartia*), then scholars and critics agree this seems to be it: in the words of the chorus, "Pride [*hubris*] breeds the tyrant / violent pride, gorging, crammed to bursting / with all that is overripe and rich with ruin— / clawing up to the heights, headlong pride / crashes down the abyss—sheer doom!"²⁹ Pride of what exactly? One answer at least is clear: his tragic ignorance of the existential enigmas of crip time and futurity.

²⁷ Kitto, 145.

²⁸ Kafer, 34.

²⁹ Sophocles, *The Three Theban Plays*, 963-67.

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Disabled White Feminist Convert: Navigating the Liminal Space between East and West, Abled and Disabled, and Honor and Shame in the Coptic Orthodox Church

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Introduction

Navigating the world as a disabled white feminist convert is to sail on the margins and in the liminal spaces of common dichotomies. As a Western-born and raised woman living in the Midwest, belonging to an Oriental (Coptic) Orthodox church, and living with a disability, cerebral palsy, I am familiar with living two opposing ways of life.² The dichotomies I am most in conversation with in my current experience are East/West, abled/disabled, and honor/shame. Faith and lived experience collide in a clash of cultures and paradigms for me. In this paper, I will explore dichotomies of East/West, abled/disabled, and honor/shame to consider disabled converts' place in the church, and how on a wider scale, the church has growing to do in its dialogue about disability and the inclusion of disabled people in its communities. Disabled, white, feminist, convert, as well as the aforementioned dichotomies will be considered as categories or defined terms, which will increase the understanding of these spaces of "in-between" and liminality. Tackling terminology is an important part of my exploration.

I cannot include the vast expanse of history of disability, gender, culture, and religion within the confines of this paper. I will focus on terms, models, and definitions as they pertain to my lived experience as a disabled white feminist convert while also acknowledging existing scholarship surrounding these labels. Some of my experience will be compared to the experience of a male disabled convert to the Coptic church. As the three dichotomies present themselves in my world, I will highlight the import of finding the liminal spaces within each one to discover my place in the Coptic Orthodox Church as a disabled white feminist convert.

To begin, I will define and discuss each of these dichotomies. I will present definitions and understandings of disability, race, feminism, and conversion in the context of the Coptic Orthodox Church and culture to seek placement in liminal spaces. Finally, models of disability which may be useful for the church will be assessed to contemplate disabled converts' future

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² Copt refers to a person of Egyptian descent, derived from the Arabic syllables Q-B-T, interpreted from the Greek, *Aigyptos*, or Egypt.

as members in the church and how models might encourage further dialogue among the three perpetually clashing dichotomies.

Definitions of Dichotomies

East/West

East is often seen as exotic, emotion-driven, politically unstable, culturally operating under an honor-shame paradigm, communal, prioritizing family, poetic or mystical. West tends to be seen as rational, governed by reason, individualistic, politically stable, and people are generally viewed as selfish. My perception and definitions of East and West are generalized, keeping in mind how these are politically and emotionally loaded terms. Scholar Edward Said is known for his work *Orientalism*, which demonstrates how geographical regions in the world became the Orient through the West's gaze and became dominated by its militaries, particularly beginning with Napoleon's invasion of Egypt in 1798.³ Said makes an important point regarding the West's label of the Orient. It is not merely Orient and Occident, or East and West, but rather, in using inherently opposing terms, we are creating and cementing of "us" versus "them," what is "the familiar," and "the strange."⁴ Geo-political and cultural differences and even the concept of "othering" people does not do justice to the dichotomy at play in the Coptic Orthodox Church situated in the diaspora. Said is critiquing the history of colonialism post-antiquity with his work and though not all of what he writes applies to my experience, much of his work stands the test of time in the academy. His understanding serves as a cornerstone definition of East and West in contrasting terms, which emphasizes how the West sees itself as militarily, culturally, and intellectually dominant. However, in my experiences in the Coptic church, East is considered superior to the West.

My own experiential understanding of the dichotomy of East/West comes from communicating with Egyptians in my church. The West has been described to me as individualistic, selfish, unconcerned with morals or honor, obsessed with success, and secular. The East is seen by Egyptians in my congregation as the cultural cradle of life, as people who think with both rationality and poetry, those who care for family values and the greater good of all people. There is still plenty of middle ground between these generalizations about East and West, a ground upon which I am consistently trying to stand in hopes of navigating labels,

³ Edward W. Said, *Orientalism* (New York: Random House, Vintage Books, 1979), 40, 42, kindle edition.

⁴ Said, 43.

definitions, and boundaries. This dichotomy in my lived experience reveals an irony: “us versus them,” or “othering,” can be found when those in the East view the West, or when those in the West view the East. The East/West dichotomy has us “othering” each other in many ways. Abled/disabled also “others” people in its dichotomy.

Abled/Disabled

In the medical model of disability, nondisabled people are non-pathological, normal, acceptable, and strong. Disabled people are weak, abnormal, and defective.⁵ The social model of disability surfaces out of a reaction to the medical model, insisting that disability is defined instead by the barriers erected by society which keep disabled people from being full participants in everyday life.⁶ Within the medical, religious, and charity models, the definable clash of able/disabled is clearest. The religious model of disability sees disability as either punishment for sins or as a test of salvation, while the charity model attends to the welfare of disabled people by viewing them as objects of pity.⁷ Models of disability help to define abled/disabled, two words which carry centuries of meaning and transformation. In current terminology, disability is often defined by the disabled person, and can involve the physical or cognitive body and its sensory experiences.⁸ Disability is also often defined in contrast to ability in reference to alleged limitations or impairments.⁹ Ability is commonly defined by abled people to indicate whether or not disabled people have lives worth living or if they can contribute to society, usually via production.¹⁰ Ability and disability also factor into the honor/shame cultural paradigm.

Honor/Shame

This is how shame and honor seem to be represented in Coptic (and Middle Eastern) culture: To bring honor to one’s family is to prioritize the good of all, rather than the good of the self. Honoring oneself happens by honoring one’s family, community, and sometimes country. Shame is brought upon one who does not abide by the code of honor which values a greater

⁵ Marno Retief and Rantsoa Letšosa, “Models of Disability: A Brief Overview,” *HTS Theological Studies/Theological Studies* 74 no. 1, a4738 (2018): 2-3.

⁶ Retief and Letšosa, 3-4.

⁷ Ibid, 6.

⁸ Rachel Adams, Benjamin Reiss, and David Serlin, “Disability,” *Keywords for Disability Studies*, eds. Rachel Adams, Benjamin Reiss, and David Serlin (New York: NYU Press, 2015), 5.

⁹ Adams, Reiss, Serlin, 6, 8.

¹⁰ Fiona Kumari Campbell, “Ability,” *Keywords for Disability Studies*, eds. Rachel Adams, Benjamin Reiss, and David Serlin (New York: NYU Press, 2015), 12-13.

good or a standard to which one must hold oneself.¹¹ There are honorable and shameful ways of living, if one chooses to consider what others in the community might think of their actions.

Scholar Zeba Crook offers a clarifying lens to examine aspects of the honor/shame dichotomy. If honor remains a culture's dominant paradigm, then honor might be considered through two arteries: attributed honor and distributed honor.¹² People's attributed honor comes from their family name and status as judged by society, and distributed honor is awarded to those who outwit, act as benefactor, or undertake a "public challenge or riposte."¹³ These are definitions applied to the ancient world and to some degree, travel into the contemporary realm quite fittingly.

In this dichotomy, honor and shame play a significant role in Coptic culture, even in the diaspora of Canada and the United States, despite its location in the geographical and philosophical West. Having grown up in the West, my own experience with the honor/shame paradigm is less than my Coptic-American counterparts. Even now, with a deeper understanding of what Crook calls the "public court of reputation," I find myself sitting outside the courtroom.¹⁴ Honor/shame is not my culture and I do not seek the approval of my church community. In a sense, I often act unwittingly in ways that may bring myself honor or shame in my own church community. For example, openly admitting my feminist position regarding women's roles in the church or choosing not to hide my disability inadvertently bring upon shame. It is easier to see how my Western, disabled white feminist convert self may bring me shame in Coptic diaspora culture, because these titles are often placed in opposition to all things Eastern, black or brown, patriarchal, abled, or cradle-Copt. Later, I will explore how my own titles or labels can be helpful while existing in liminal spaces, but for now, they exist in contrast to the honor/shame cultural paradigm. Having explored all three thematic contradictions, we

¹¹ Valentine M. Moghadam, "Patriarchy in Transition: Women and the Changing Family in the Middle East," *Journal of Comparative Family Studies* 35, no. 2 (Spring 2004): 145, 155-156. See also Gideon M. Kressel and Unni Wikan, "More on Honour and Shame," *Man* 23 no. 1 (Mar. 1988): 167-168. Febe Armanios helpfully discusses Coptic female virtue in the context of honor and shame in a way that highlights the paradigm and pressure upon women to protect their reputation. Febe Armanios, "The 'Virtuous Woman': Images of Gender in Modern Coptic Society," *Middle Eastern Studies* 38 no. 1 (January 2002): 110-130.

¹² Zeba Crook, "Honor, Shame, and Social Status Revisited," *Journal of Biblical Literature* 128 no. 3 (Fall 2009): 610. Crook makes a persuasive case for altering Bruce Malina's definitions of ascribed and acquired honor into attributed and distributed honor because the ultimate arbiter of both is what she terms, "public court of reputation." Crook, "Honor, Shame, and Social Status Revisited," 593.

¹³ Crook, 610.

¹⁴ *Ibid.*, 593.

can proceed in parsing aspects of disabled, white, feminist, and convert, all parts of my identity as a human and member of the Coptic Orthodox Church.

Disabled

I am Coptic Orthodox and I am disabled. My disability is cerebral palsy. I am theologically Coptic but will never be ethnically or culturally Coptic. My whole being encounters this ancient church by constantly bumping up against giant, looming paradigms. These paradigms often seem like obstacles in the sanctuary in which I am fighting to find my place to prostrate myself before God. In the past I would have identified my whiteness, woman-ness, or feminist-ness as the reason I struggled to enter the Coptic Orthodox Church. I now include the part of my identity which I had previously endeavored to hide: my disabled-ness. It was not a lens through which I viewed my struggle as a convert searching for community. Finding inclusion as a convert is not easy in the Coptic church, and my disability tends to make participation much more difficult.

Taking time over the last four years to radically accept myself as a disabled woman has given me space to consider just how my disabled body encounters the church into which I am grafted by baptism. As my body betrayed my efforts to hide its flaws, I found myself navigating a church and its demands that leave little space for disabled bodies' participation. The rigors of Orthodox Christianity are many— services over three hours long, standing almost the entire time, prostrations, over two hundred possible days of fasting, lengthy retreats and events, and volunteering opportunities which create community but also fail to include those who cannot withstand their physical or mental demands.

Technically, a Coptic Orthodox worshipper is expected to stand throughout the divine liturgy, barring prostrations or kneeling portions of the service. Once, a well-intentioned priest told me that I was “allowed” to sit through the entire liturgy, except at the Gospel reading, with “special absolution.” At the time, I saw his kindness, and only afterward felt the sting of the idea that my disabled body needed pardoning for not fulfilling its obligation of needing to stand more than sit during worship. In the church, standing is seen as bringing honor or respect to Christ, in the presence of the Holy Body and Precious Blood, the Communion elements.

I have always admired my Coptic sisters and brothers in their endeavor to preserve their faith. Copts are dedicated to the survival of their heritage, particularly in the United States as such forces like assimilation and Western mores feel like competing influences. Coptic

communities want to remain Coptic, which keeps them insular at times. Closing ranks against outsiders or those who may be a threat to the church, its culture, or its survival, is not an uncommon reaction. Fear and rigidity help maintain cultural and ethnic boundaries. Flexibility and adaptability open borders and change a community's outlook toward inclusion as its membership becomes more diverse in ability. When ranks close, people like me who may be disabled or white may find themselves unwelcome in the community.

White

Racially, I am white. Definitions of race sometimes demarcate between white and non-white, though to me, this is unhelpful given we live in a blended world. Ethnically, I am a Polish-Finnish-German-American. Ethnicity may be a more useful distinction than whiteness, since "white" is not necessarily its own culture. My Eastern European values sometimes conflict with Coptic values. For example, in my Germanic Lutheran culture growing up, our church services started promptly, but when I started attending Coptic services in 2012, showing up at promptly often meant arriving before the priest! My Finnish grandmother and my own father are stoic, quiet, and stern. Sometimes Egyptian social gatherings overwhelm this introverted Northerner. Attending Coptic liturgies often means I am the only white person at the service and have been welcomed with, "White people at our church? What are you doing here?" I was surprised to learn that sometimes the word "Protestant" is used synonymously with "lazy," in Coptic culture. Protestant services are commonly shorter, but Coptic Orthodox Christians are often unaware of hours-long services and stringent fasting practices in charismatic, Holiness, Pentecostal, historically Black churches, and other Christian denominations. Being in the racial minority in my church has given me perspective about racism and unconscious bias. My whiteness is a marker of my outsider status in the Coptic Church, as I am usually one of a few white people in attendance. Similarly, I am often one of a few feminists in the church, and certainly am more outspoken about sexism in the church than most of its members.

Feminist

As an educated self-identifying feminist, I firmly believe that both sexes are equal before God in earthly and theological or biblically based gender roles.¹⁵ I am an egalitarian rather than

¹⁵ I subscribe to the Oxford English Dictionary's definition of feminist, which is: "Of, relating to, or advocating the rights and equality of women." No Author. "Feminist, adj. and n.," *OED Online*, December 2021, Accessed February 20, 2022, Oxford University Press, <https://www-oed-com.fuller.idm.oclc.org/view/Entry/69193?redirectedFrom=feminist>.

complementarian. Egyptian women may find their roles reduced to being wives and mothers in the domestic cultural sphere but theologically, Orthodoxy sees marriage as egalitarian with both husband and wife in obedience to the other, though through different roles.¹⁶ As a white feminist growing up in the Midwest, a female pastor was the head of our country congregation and I never once felt pressured to get married, have children, or remain in a domestic role. Thus, Egyptian cultural understanding of women's "roles" and the culture transplanted to the diaspora are outside of my firsthand experiences. I recognize inequalities as a Western feminist and bring this cognizance with me as a member of the Coptic church.

Coptic women are often well-educated and pursue careers alongside marriage and having children.¹⁷ Some Coptic women have fought for the restoration of the ancient female diaconate and have seen it to some success, though only as chanters, not readers or those who can become full deacons.¹⁸ In the academic realm, Coptic scholars like Donna Rizk Asdourian have spoken of the need for female participation in the diaconate in the Coptic Orthodox Church.¹⁹ I am not alone in my concern that the Coptic Orthodox Church is denying a charism to women given through apostolic succession. My voice in the debate does not carry far, because I am removed from the cultural situation that plays a part in resisting the full restoration of the diaconate. Being a Western feminist formerly of a progressive Protestant tradition and well-educated in the Scriptural and traditional arguments used to oppress women only adds to my marginalized status in the church. A white feminist is less welcome in the Coptic community, unless I were to conform to more complementarian and oppressive structures in the church culture. Adding the status of convert creates another layer of marginalization to my identity and existence in the Coptic church.

¹⁶ Berit Thorbjørnsrud, "Born in the Wrong Age: Coptic Women in a Changing Society," in *Between Desert and City: The Coptic Orthodox Church Today*, eds. Nelly van Doorn-Harder and Kari Vogt, (Eugene, OR: Wipf & Stock, 2012) 175, 179, 187-188. Though St. John Chrysostom advocates for a complementarian marriage, contemporary Coptic priests in the West are revisiting the concept of egalitarianism and equality between male and female in marriage. See H.G. Bishop Moussa, "Marriage and Family Life," *Life in Christ*, St. Mary's & St. Shenouda's Coptic Orthodox Church, accessed February 26, 2022, <https://smass.co.uk/life-in-christ/marriage-family-life>. See John Chrysostom, "Homily 20 on Ephesians," trans. Alexander Gross. *Nicene and Post-Nicene Fathers, First Series* Vol. 13. ed. Philip Schaff (Buffalo, NY: Christian Literature Publishing Co., 1889), np, Revised and edited for *New Advent* by Kevin Knight.

¹⁷ Berit Thorbjørnsrud, "Born in the Wrong Age," 179-180. For more information about education in the Coptic diaspora, see Nora Stene, "Into the Lands of Immigration," in *Between Desert and City: The Coptic Orthodox Church Today*, eds. Nelly van Doorn-Harder and Kari Vogt, (Eugene, OR: Wipf & Stock, 2012), 254-262.

¹⁸ Mariam Youssef, PhD, leads the female diaconate in the Los Angeles diocese of the Coptic Orthodox Church and is in charge of training girls and women in the role of chanter. She began the female diaconate program at St. John Coptic Orthodox Church in West Covina, California.

¹⁹ Donna Rizk Asdourian, "Women for the Church," *Public Orthodoxy Blog, Orthodox Christian Studies Center of Fordham University*. January 9, 2018. January 15, 2022.

Convert

As a white disabled feminist convert, I have chosen to enter a rich religious and ethnic tradition quite different from my own background. In theological terms, I was called into the church by God. Converts are the very basis of Christianity through evangelization. As its ethnic and theological splits across centuries have divided it, converts are one way of continuing the church and helping it to evolve across boundaries like Western, disabled, white, or feminist. As a member of the Coptic Orthodox Church, my status as a disabled woman who ascribes to feminism and chooses to openly defy traditional gender roles with my continued ecumenical education and singleness, I have not chosen an easy path. I am not alone in choosing this path, and considered my journey alongside another, a disabled male friend in the Coptic church who has also converted into the faith. In my interview with him, I found both parallels and divergences in our journeys and experiences. Here, I discuss conversion and disability with him to offer an added layer of illumination to a disabled convert's experience in the Coptic church.

Disabled Converts in the Coptic Orthodox Church: A Conversation

While there are disabled ethnically Coptic people in the church, it is rare to find disabled Coptic converts in the church. As I write this, I have only found one other disabled convert into the Coptic church, my friend, Daniel Michalski. Perhaps we are unicorns. Daniel is also Polish-American, like me. We met in an online venture of mine through Twitter to create a space for disabled Orthodox Christians. I asked Daniel if he would be willing to allow me to interview him about his experience in the church as a disabled convert, and he graciously agreed to share some of his experiences.

My interview with Daniel gave me new perspective on being a disabled male convert into the Coptic Orthodox Church, particularly because Daniel's disability, autism, is non-apparent whereas my own physical disability is apparent to others. Parts of his experience surprised me because they are utterly different from my own. Daniel and I are both technically members of mission churches marketed toward American converts.²⁰ My priest is an Egyptian, Arabic-speaking, culturally Middle-Eastern man. Our parish still has Arabic liturgy at least once a month. Daniel's priest does not speak much Arabic at all. His parish is also more comfortable

²⁰ Interview with Daniel Michalski, January 22, 2022, by Elizabeth Staszak.

with women's participation as they have three deaconesses. My church has no deaconesses and has never mentioned wanting to restore the ancient apostolic charism.

Daniel, like many disabled people, questions whether his disability is a disability at all. His autism can be a gift, allowing him to traverse cultural boundaries without questions or culture shock, giving him the opportunity to easily blend into unfamiliar places, like the Coptic Orthodox Church. His disability, he explains, is found in his being more easily overwhelmed by sensory experiences as an autistic man.²¹

The church hierarchy has accepted Daniel's participation in the diaconate and allows him to adapt as necessary for his disability. Adaptation for Daniel might mean fully participating as deacon one week, while standing off to the side another week when he may be experiencing some sensory overload. He has had to "overcome" his disability by training himself to overcome his nervousness or discomfort in social interactions and communicating his needs to others. Daniel communicates his needs as a disabled person and is learning to say no when he cannot do something for his service.²²

Daniel's conversion was simply a theological one. The culture of the church does not trouble him, though he admits to assimilating over time to small cultural aspects. For example, out of respect for his neighbor, Daniel does not cross his legs in church because it would expose the bottom of his foot to his neighbor, something not appreciated in Middle Eastern culture. Daniel is Western but tends to fit into Eastern culture too. Daniel is aware of the patriarchal nature of the church and is obedient to it. He takes the hierarchy seriously and participates in the church as a deacon. Aware of the church's tendency toward sexism, he tries to practice inclusivity with his church's three deaconesses to align with the ancient church's practices of including women in the diaconate.²³ Daniel supports women as vital contributors to the liturgy and services of the church community.

I was jealous of Daniel's experience in his church. Able to see disparities between men and women in the church, acknowledge cultural differences whilst navigating them with ease, and navigate his disability's needs, Daniel seems to thrive in the church. I have not had such experiences. Daniel has maleness and a non-apparent disability in his favor. As a woman with

²¹ Ibid.

²² Ibid.

²³ Interview with Daniel Michalski, January 22, 2022, by Elizabeth Staszak. Daniel supports deaconesses serving in the altar, reading the Gospel, and helping with baptisms.

an apparent disability as well as theological training, my attempts to find community in the church as a convert are not as successful. Social currency in the church comes from active, consistent participation in church life, which takes place throughout the week rather than only on Sundays. Daniel's disability might keep him from full participation as a deacon, but my disability and accompanying chronic pain and fatigue keep me from full participation in the liturgy, let alone in other weekly events like Bible study, volunteer service, Vespers, or prayer meetings.

I do not have Daniel's skill of fluidly navigating cultural boundaries. His autism allows him to process information differently from how my brain processes information. He is a man in a man's world, the Coptic Orthodox cultural world, and has also transcended boundaries because his disability is like his superpower.

Models of Disability and Orthodox Christianity

After talking with Daniel and recognizing that people with disabilities have such different experiences in the Coptic church, I thought it prudent to consider disability in the Coptic Orthodox Church by using various disability models. Exploring disability through the lens of church culture is different from exploring disability through an Orthodox theological lens. Church communities tend to be diverse in opinion and understanding about disability and do not necessarily accurately subscribe to one Orthodox theology of disability.

Orthodox Christianity generally subscribes to the religious or moral model of disability in the sense that disability can be a test or an act of suffering to be accepted by the disabled individual, even to the point that one's disability can be useful for one's salvation.²⁴ I cannot deny the power and prevalence of this understanding and do indeed find my suffering useful for my own salvation.

Cerebral palsy, my disability, comes with a host of accompanying health issues and requires continuous care. My own priest does try to accommodate my disability. He is my spiritual father and has met my disability needs with some understanding. He also encourages me as I wrestle with physical complications. The limits model is also useful for my own

²⁴ Summer Kinard, *Of Such is the Kingdom: A Practical Theology of Disability* (Chesterton, Indiana: Ancient Faith Publishing, 2019), 44. Typically, churches have been fertile grounds for the moral or religious model of disability. A religious understanding of disability may be viewed as an individual's punishment for sin, a test of faith, or an ordinary act of suffering given for one to endure in life.

circumstances. Recognizing my physical limitations helps me participate more fully in my faith tradition.²⁵

Sally Campbell Galman discusses conversion and acceptance of customs and demands of a religion as an identity choice.²⁶ As a convert, I have chosen to enter a culture which may view my disability as something shameful or to be hidden, even a culture which would prefer I hide myself.²⁷ The cultural agreement of the church is that amid incredible suffering, people in the church manage to attend no matter what. People will drive for hours to attend a Divine Liturgy and risk their lives to attend despite the concern that bombs have been planted under seats. Why should my cerebral palsy be an excuse for not attending a service?²⁸ Cultural logic dictates participation. As a convert, I have made a choice to commit to the grueling church schedule. Besides, suffering is just part of life in the Orthodox Way. I make these final statements facetiously, because this “logic” is cultural and not necessarily transcendent or universal.

The Coptic church also subscribes to the medical model, as many Copts work in the medical profession as doctors, dentists, scientific researchers, and more. Disability is understood as a medical condition. Many monks and nuns suffered from health conditions and have sought treatment while also forcing their bodies to match desert asceticism, often dying relatively young, like Mother Erene of modern Egypt.²⁹ Though the medical model can be insightful and perhaps aid in breaking down cultural or religious stigma surrounding disability, it does not recognize how it perpetuates unhelpful ideas about disability by viewing disability as deficiency. With medical and religious models in mind, as well as the dichotomies of East/West, able/disabled, and honor/shame, the liminal spaces become clearer.

²⁵ Deborah Beth Creamer, “Limits and Disability Theology,” in *Disability in Christian Theology: Embodied Limits and Constructive Possibilities*, Academy Series (Oxford: Oxford University Press, 2009), 94.

²⁶ Sally Campbell Galman, “Un/Covering: Female Religious Converts Learning the Problems and Pragmatics of Physical Observance in the Secular World,” *Anthropology & Education Quarterly* 44 no. 4 (December 2013): 425.

²⁷ Marina Z. Nakhla, “Why Do You Walk Like That?” *Coptic Voice*, October 17, 2017, accessed January 16, 2022. <https://medium.com/coptic-voice/why-do-you-walk-like-that-74f5ecca4ea>. Nakhla discusses her parents’ resistance to pressure from the church community to limit Marina’s participation in church or keep her at home.

²⁸ In recent history, Copts have been the target of Daesh-sponsored terrorist attacks. See BBC News, “Egypt’s Coptic churches hit by deadly blasts on Palm Sunday,” *BBC News*, April 9, 2017, Accessed February 13, 2022, <https://www.bbc.com/news/world-middle-east-39544451>.

²⁹ The Convent of the Great Martyr of St. Philopater Mercurius “Abi Seifein,” for Nuns, *Tamav Erene: The Jewel of Heaven and the Beacon of Monasticism* (Old Cairo, Egypt: Nubar Printing House, 2007), 120, 125-126.

Liminal Spaces and Conclusions

The more I exist on the margins, the broader the view I take of the church and its culture. To my benefit, I am able to exist in the liminal spaces of the proposed dichotomies. I am disabled in an ableist, honor-based culture. I am a shameless feminist in an honorable, patriarchal place. I am a convert to an insular community. Options of navigation lay before me. I can choose when I conform and when I resist, swimming around the harsh binaries of dichotomy. Being Western in an Eastern place does not mean God hears my prayers less than Coptic prayers. Being disabled in an ableist culture means I can speak against injustice and support others who may share my experiences with or feelings about disability. Being shameless in a culture of honor gives me the freedom to present myself before God transparently, unafraid of community judgment. There is opportunity to build bridges between cultures and modes of operation as I make friends in the community and continue living in the Western world. Embracing mystery in the Oriental church helps me make sense of my reason-driven culture.

Models of disability which may prove useful in both the liminal spaces and in the Coptic church are: the religious model, the limits model, and the social model. If the church were to theologically dig into its religious model, it would find in its riches not only the act of suffering with disability, but also Jesus' radical inclusion of people with disabilities made to be themselves in God's kingdom.³⁰ Going further, the social model could help the church recognize how it sets up barriers which exclude people with disabilities.³¹ The social model encourages people to become more adaptable and flexible, and in this case, would allow disabled people to attend or pray in liturgies, participate not only as observers or learners, but also as serve leaders in its roles and activities.³² The limits model allows people to recognize their limitations and work within them.³³

Jesus' life on earth showed us how he found people on the margins and in the liminal spaces of society, saw their worth, and made a place for them in the kingdom of God. The Orthodox church testifies to this salvific work, and yet finds itself trapped by the binary

³⁰ John Chryssavgis, "Ministry, Disability, and Brokenness: Orthodox Insights into the Authority of the Priesthood," *Pacifica* 12 no. 2 (June 1999): 176-177.

³¹ Retief and Letšosa, 3.

³² See Charlotte Riggle, "Disability in the Orthodox Parish: A Call to Love," *Orthodoxy in Dialogue*, September 8, 2019, accessed January 16, 2022, <https://orthodoxyindialogue.com/2019/09/08/disability-in-the-orthodox-parish-a-call-to-love-by-charlotte-riggle/>. Riggle offers ways in which Orthodox parishes can be considerably more inclusive towards people with disabilities.

³³ Creamer, 93.

dichotomies of East/West, able/disabled, and honor/shame. No one person fits or completely ascribes to such dichotomies and when dichotomies become more important than inclusivity, the church loses its creative love and with it, disabled members. Many times, I have felt my disabled white feminist convert self slowly backing away from the church because I did not fit into its dichotomies. I longed for nuance and acceptance as my Western, rational, moderate self in an Eastern, mystery-loving, ascetic church. Conversion is about sacrifice, giving up one way of life for another, but it does not mean one must lose vital parts of their identity or personhood. Conversion is about living a new life in a redeemed self. Redemption does not erase our backgrounds and identities; it enriches them and brings them into a larger community.

My disabled white feminist convert self can exist in the liminal spaces between giant, contrasting dichotomies and find my place in the Coptic Orthodox Church. My disabled self can exist without shame and with honor in a culture which might prize ability over disability. The church can tap into its ancient roots going all the way back to the man who leads them—Jesus. Jesus confronted East/West when he was born a Jew and worked within the Roman Empire. He recognized all abilities and saw how society disabled people with differences, bringing the marginalized into community. Jesus acted shamelessly in order to bring honor to people who had lost it. Jesus is how I know there is a place for me in the Coptic Orthodox Church. If the church is willing to consider new models of thinking about disability and hearken back to its start, it will find disability inclusivity in the unlikely, in-between spaces, where it first found Christ.

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The Moderating Effect of Positive Sexual Self-Concept on the Relationship between Disability Impact and Satisfaction with Life

Alexandra Kriofske Mainella¹ and Bianca Tocci²

Individuals with disabilities live, work, love, and exist in society, alongside their non-disabled peers, with the same spectrum of life experiences and identities. This study considers the impact of disability and sexual self-concept on individuals with the specific disabilities of cerebral palsy and spina bifida. Both diagnoses are neurological developmental disabilities that impact physical function, muscle, and movement and are diagnosed in childhood. Disability can have an impact on a person's relationships, including romantic and sexual, sexual self-concept and life satisfaction. Beneficial experiences in life, including strong social support and relationships, can positively impact the life satisfaction of a person with a disability regardless of the impact of their disability or disabling condition. Thus, the present study examines the interactions between positive sexual self-concept and disability impact on the life satisfaction of individuals with cerebral palsy and spina bifida.

Life Satisfaction

Satisfaction with life is a construct often considered within the literature on adjustment and adaptation to disability.³ Life satisfaction is part of the global construct of happiness studied by Ed Diener⁴ and is subjective, measured through positive variables and can be globally assessed.

Life Satisfaction and People with Disabilities

Beatrice Wright⁵ was a pioneer in work with people with disabilities using a positive, strength-based approach; she understood that focusing on assets of individuals with disabilities, rather than deficiencies, can reduce the impact of disability itself. Positive psychosocial factors, such as self-esteem and optimism, can lead to more success in adaptation to disability as well as in employment, and psychological and physical well-being.⁶

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³ Fong Chan, Elizabeth Da Silva Cardoso, and Julie Chronister, *Understanding Psychosocial Adjustment to Chronic Illness and Disability: A Handbook for Evidence-Based Practitioners* (New York: Springer Publishing Company, 2009), 228-230.

⁴ Ed Diener, Robert A. Emmons, Randy J. Larsen, and Sharon Griffin, "Satisfaction with Life Scale", *Journal of Personality Assessment* 49, (1985): 71-75.

⁵ Beatrice Wright, *Physical Disability: A Psychosocial Approach* (New York: Harper and Row, 1983).

⁶ Chan, Cardoso, and Chronister, 220-221.

While people with disabilities can and do experience life satisfaction, they also experience limitations based on disability. These limitations can impact attainment of personal goals including those regarding social and sexual relationships. People with disabilities experience social isolation through institutional and personal systems but also report a desire to have relationships (i.e., friendships, romantic and of a sexual nature).⁷

Sexual Self Concept

Satisfaction with life has not been widely studied in terms of positive sexual self-concept factors, but empirical analysis has suggested that global measures of life satisfaction would be more all-encompassing with the addition of sexual well-being.⁸ Sexual self-concept is the moderating variable of this study and is, for the purposes of this research, comprised of four parts: sexual self-esteem, sexual self-efficacy, sexual optimism, and sexual anxiety.

Sexual Self-Esteem

Self-esteem is generally defined as a positive view of oneself and one's worth.⁹ Positive self-esteem has been linked with psychosocial adjustment to disability and adaptive coping.¹⁰ While Wright found there are no differences in global personality of people with and without disabilities,¹¹ studies have certainly connected impact of disability stigma, health issues and concerns, and learning challenges with self-esteem.¹² Sexual self-esteem is a variable of sexual self-concept, characterized by positive view of one's sexual self within the context of healthy sexuality.¹³

Sexual Self-Efficacy

Self-efficacy is the belief about one's ability to perform and succeed. Self-efficacy motivates behavior as well as self-assessment of behaviors. Those with strong self-efficacy are able to

⁷ Nancy Murphy and Ellen Roy Elias, "Sexuality of Children and Adolescents with Developmental Disabilities," *American Academy of Pediatrics*, 118, no. 1 (July 2006), 398-403.

⁸ Marc Hooghe, "Is Sexual Well-being part of Subjective Well-being? An Empirical Analysis of Belgian (Flemish) Survey Data using an Extended Well-being Scale," *Journal of Sex Research* 49, no. 2-3 (May, 2012): 264-273.

⁹ Albert Bandura, *Social Foundations of Thought and Action: A Social Cognitive Theory*, (Englewood Cliffs, NJ: Prentice Hall, Inc, 1986

¹⁰ Chan, Cardoso, and Chronister, 111-112.

¹¹ Wright, *Physical Disability*.

¹² Mark Ferro and Michael Boyle, "Self-concept among Youth with a Chronic Illness: A Meta-analytic Review," *Health Psychology* 32, no. 8 (2013): 846.

¹³ Sharon Rostovsky, Olga Dekhtyar, Pamela Cupp, and Eric Anderman, "Sexual Self-Concept and Sexual Self-efficacy in Adolescents: A Possible Clue to Promoting Sexual Health?" *Journal of Sexual Research and Policy* 45, no. 3 (July-September 2008): 284.

recover from failures and to set their own goals.¹⁴ Because people with disabilities are often required to adapt and adjust to the inaccessibility of life, self-efficacy is particularly important for this population, including those with spina bifida and cerebral palsy. For people with disabilities, self-efficacy has been correlated with both life satisfaction and adjustment to disability.¹⁵ Sexual self-efficacy is correlated with lower risk sexual behaviors and higher reports of sexual satisfaction.¹⁶ Sexual self-efficacy, in the current study, is defined as belief in ability to meet one's own sexual needs.

Sexual Optimism

Optimism is a subconstruct of a higher order positivity construct called Psychological Capital (PsyCap) including hope and resilience. PsyCap, alongside positivity is associated with good physical health and higher self-reported life satisfaction.¹⁷ For people with disabilities, an optimistic approach is linked with more life satisfaction, stronger relationships, and more success in reaching personal goals.¹⁸ In the current study sexual optimism is defined as the belief in eventual reward in one's sexual future.

Sexual Anxiety

Anxiety is considered a typical reaction to stressful feelings and events. Anxiety can be beneficial in coping with dangerous situations as well as in increased satisfaction with performance.¹⁹ People with disabilities such as spina bifida and cerebral palsy commonly experience anxiety as part of psychosocial adaptation to disability.²⁰ Meta-analyses have shown that anxiety outside typically occurring and beneficial anxiety, is linked to lower subjective well-being measures, negatively impacting emotional health and social function in people with a variety of disabilities.²¹ Sexual anxiety is defined as fear or worry regarding sexuality, impacting sexual function and desire. Like general anxiety, sexual anxiety can be experienced

¹⁴ Albert Bandura, *Self-Efficacy*, (New York: Academic Press, 1984).

¹⁵ Chan, Cardoso, and Chronister, 268.

¹⁶ Rostosky, Dekhtyar, Cupp, and Anderman, 282.

¹⁷ Michael Scheier and Charles Carver, "Optimism, Coping, and Health: Assessment and Implications of Generalized Outcome Expectancies", *Healthy Psychology* 4, no. 3 (1985): 245-247.

¹⁸ Chan, Cardoso, and Chronister, 256.

¹⁹ Elliot Cohen, *The Dutiful Worrier: How to stop Compulsive Worry without Feeling Guilty* (Oakland, CA: New Harbinger Publications, 2011), 50-53.

²⁰ Hanoeh Livneh and Lisa Wilson, "Coping Strategies as Predictors and Mediators of Disability Related Variables and Psychosocial Adaptation: An Exploratory Investigation, *Rehabilitation Counseling Bulletin* 46, no. 4 (July 2003): 194-208.

²¹ Christophe Maiano, Sylvain Coutu, Danielle Tracey, Stephanie Bouchard, Genevieve Lepage, Alexandra Morin, and Gregory Moullec, "Prevalence of Anxiety and Depressive Disorders among Youth with Intellectual Disabilities: A Systematic Review and Meta-analysis," *Journal of Affective Disorders* 236, (August 2018): 230-242.

seldomly or persistently, characterized as dysfunction.²² Sexual anxiety in the current study is a negative factor in sexual self-concept.

Disability Impact

In the United States, an estimated 1 in 4 people have a disability of some kind.²³ Cerebral palsy is the most common disability impacting motor function diagnosed in the US²⁴ and more than 75% of people diagnosed with spina bifida in childhood live to adulthood.²⁵ Individuals with disabilities, including spina bifida and cerebral palsy, experience a spectrum of impact of their disability from mild to severe.

The World Health Organization²⁶ created a model to conceptualize the impact of disability called the International Classification of Functioning Disability and Health (ICF). The model looks at an individual's diagnosis or condition (spina bifida and cerebral palsy, in the current study) and the way it interacts with body function and structure, the activities a person is able to participate in and the level of that participation, and finally contextual factors—both environmental and personal.²⁷

Current Study

People with disabilities, their families, caregivers, social networks, and service providers are often looking for ways to increase life satisfaction, mitigate the disability impact, and provide opportunities for social connections. Research suggests that social connections can improve life satisfaction; romantic and sexual relationships can improve one's self-concept, sexual self-concept, and satisfaction with life. Examining sexual self-concept as a moderator of the relationship between disability impact and life satisfaction will allow for further exploration of this area.

²² Oluwatosin Adekeye, Taiwo Lateef Scheikh, and Olufunke Tmitope Adekeye. "The Assessment and Management of Sexual Anxiety among Selected University Undergraduates," *Gender and Behavior* 10, no. 1 (June 2012): 4523-4532.

²³ "Disability and Health Data System," Centers for Disease Control, <https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index>.

²⁴ "Data and Statistics for Cerebral Palsy," Centers for Disease Control, last modified October 21, 2019, <https://www.cdc.gov/ncbddd/cp/data>.

²⁵ Robin Bowman, David McLone, John Grant, Tadanori Tomita, and Joy Ito, "Spina Bifida Outcome: A 25-year prospective," *Pediatric Neurosurgery* 34, no. 3 (March 2001): 114-120.

²⁶ WHO, "International Classification of Functioning, Disability and Health", Geneva: Switzerland (2001) <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>

²⁷ See, Note 24.

Method

Participants

104 adults with cerebral palsy, spina bifida and other neurodevelopmental disabilities participated in the study. The participants described themselves as White (83.7%), Latinx or Hispanic (3.8%), African American (2.9%), Asian American (2.9%), and Other (3.9%). The majority of the participants identified as female (64%), with 36.5% identifying as male and 2% identifying as nonbinary gender identity. About half of the participants were in a relationship (49%) and 51% were single.

Procedures

Following approval from the institutional review board (IRB), participants were recruited from service and advocacy organizations, through online support groups for people with cerebral palsy and spina bifida and through snowball sampling. Participants were eligible if they were (a) 18 years of age and older and (b) diagnosed with cerebral palsy, spina bifida, or other neurodevelopmental disabilities impacting physical function. Exclusion criteria included anyone falling into the prior two categories with a co-occurring intellectual disability or not functioning as their own guardian and therefore unable to give informed consent. Once deemed eligible, participants were then directed to a series of questions including informed consent, a demographics questionnaire, and the study's measures.

Measures

Demographics: A demographics questionnaire was given to each participant to gain information on identity, relationship status, education level, disability and living situation.

Disability Impact: Disability impact was measured using the World Health Organization Disability Assessment Schedule (WHODAS),²⁸ which is a 12-item measure of disability impact. The participants, in responding to the questions asked, rated their ability regarding the specified activities over a period of 30 days with a five-point scale ranging from no difficulty to extreme difficulty. Overall, the WHODAS is found to have good psychometric properties and high reliability with a Cronbach's alpha of .98 as well as face validity; research on the WHODAS and its ability to measure disability effects found that it was an accurate

²⁸ World Health Organization, "Disability Assessment Schedule." (Geneva: Switzerland, 2010).

measurement as defined by the ICF model. The Cronbach's alpha found for total scores for the sample in the present study was .78.

Sexual Self-Concept: Four subscales of the Multidimensional Sexual Self Concept Questionnaire (MSSCQ)²⁹ were used to assess sexual self-concept. The full MSSCQ is a 100-item measure in which respondents answer on five-point scale ranging from 1 (not at all characteristic of me), to 5 (very characteristic of me). Overall Cronbach alpha coefficients could not be found, but the subscales are considered to be more than adequate, ranging from .72-.94.³⁰ The four subscales used together in the present study had a Cronbach's alpha of .71.

The sexual anxiety subscale contains five questions about discomfort or tension with sexual aspects of life. The Cronbach alpha coefficient for this subscale was found to be .84.³¹ The Cronbach's alpha coefficient for the sample in the present study for the MSSCQ sexual anxiety subscale was .86.

The sexual self-efficacy subscale contains five questions about belief in ability to deal with sexual needs, desires, and problems. The Cronbach alpha coefficient for this subscale was found to be .85.³² The current study found a Cronbach's alpha coefficient of .80.

The Sexual Optimism subscale contains five questions about future positive expectations regarding sexual life. This subscale was found to have a Cronbach's alpha of .78.³³ The Cronbach's alpha for participants in the current study for the MSSCQ Sexual Optimism subscale was found to be .67.

The sexual esteem subscale has five questions regarding the respondents' pride and positive feelings about their ability to handle their own sexual desires and experiences. This subscale was found to have a Cronbach's alpha of .88.³⁴ In the present study the Cronbach's alpha for the MSSCQ Sexual Esteem subscale was .83.

Satisfaction with Life: Satisfaction with life was measured using the Satisfaction with Life Scale (SWLS).³⁵ The SWLS is a five-item measure designed to gauge the construct of life

²⁹ William Snell, "Measuring Multiple Aspects of the Sexual Self-Concept: The Multidimensional Sexual Self-Concept Questionnaire" In *Handbook of Sexuality-Related Measures* Robin Milhausen, John Sakaluk, Terri Fischer, Clive Davis & William Yarber, ed., (New York: Routledge, 2011), 545.

³⁰ Robin Milhausen, John Sakaluk, Terri Fisher, Clive Davis & William Yarber, ed., *The Handbook of Sexuality Related Measures* (New York: Routledge, 2020), 550.

³¹ See, Note 28.

³² See, Note 28.

³³ Ibid.

³⁴ Milhausen, Sakaluk, Fisher, Davis, and Yarber, 547.

³⁵ Diener, Emmons, Larsen, and Griffin.

satisfaction through self-report. The five questions are answered on a seven-point scale from 1 (strongly disagree) to 7 (strongly agree). The SWLS is scored by adding the total score which reflects the degree of life satisfaction (ranging from 5-35). The SWLS has been evaluated for reliability and validity and is found to have good internal consistency with a Cronbach's alpha of .88. Construct validity for the SWLS was found through correlations with other global happiness and life satisfaction scales. The measured construct of satisfaction with life and overall happiness had good convergent and discriminant validity for this scale.³⁶ The Cronbach's alpha coefficient found for the sample in the present study for the SWLS was .91.

Data Analysis

Analyses were conducted using SPSS v.24. Correlations were first calculated to examine the relationship between disability impact and satisfaction with life. Then PROCESS was used to test the moderated effect of sexual self-concept on the relationship between disability impact and satisfaction with life. PROCESS³⁷ is an SPSS program package that uses regression analysis to estimate moderation. Prior to running the moderation analysis, the correlation between the outcome variable (Life Satisfaction) and possible covariates was examined (i.e., gender, racial/ethnic identity, relationship status).

Results

The first hypothesis stating that higher levels of sexual self-concept would be associated with higher life satisfaction was supported. In this analysis, sexual self-concept served as the independent variable with life satisfaction as the dependent. The analysis showed both the overall model $F(1, 104) = 106.9, p < .001, R^2 = .35$, and the interaction between sexual self-concept and satisfaction with life $B=.47, p < .001, 95\%$ confidence interval = [.3083, .6399], $t = 5.61, p < .001$ were significant.

The second hypothesis, that the relationship between disability impact and satisfaction with life would be stronger among those who had higher sexual self-concept scores was also supported. In this analysis, disability impact served as the independent variable, satisfaction with life was the dependent variable, and sexual self-concept was the moderating variable. The analysis showed both the overall model $F(1, 104) = 106.9, p < .001, R^2 = .35$, and the interaction

³⁶ Rosemarie Kobau, Joseph Snizek, Matthew Zack, Richard Lucas, and Adam Burns, "Wellbeing Assessment: An Evaluation of Wellbeing Scales for Public Health and Population Estimates of Wellbeing among US Adults", *Applied Psychology: Health and Wellbeing* 2, no. 3(May 2010): 272-297.

³⁷ Andrew Hayes *Introduction to Mediation, Moderation, and Conditional Process Analysis: A Regression-Based Approach* 3rd Ed. (PLACE: Guilford Press, 2022).

between disability impact and sexual self-concept were significant. The conditional effect of disability impact on satisfaction with life showed a significant relationship among people who had higher levels of sexual self-concept at the 25th, 50th and 75th percentiles ($B = -.32$, 95% CI = $[-.45, -.19]$, $t = -5.10$, $p < .001$; $B = -.47$, 95% CI = $[-.58, -.36]$, $t = -8.47$, $p < .001$; $B = -.55$, 95% CI = $[-.69, -.39]$, $t = 7.34$, $p < .001$).

Finally, a moderation analysis was explored for each level of sexual self-concept on the relationship between disability impact and life satisfaction. Disability impact was the independent variable, life satisfaction was the dependent variable, and sexual self-concept was the moderating variable in the model.

In the sexual self-concept moderation, the relationship between disability impact and life satisfaction was moderated by sexual self-concept. Both the overall model, $F(1, 104) = 5.76$, $p < .05$, $R^2 = .36$ and the interaction term $B = -.0072$, 95% CI = $[-.0132, -.0013]$, $t = -2.40$, $p < .05$ were significant. The conditional effect of disability impact on life satisfaction showed a significant relationship between disability impact and life satisfaction. (See Figure 1).

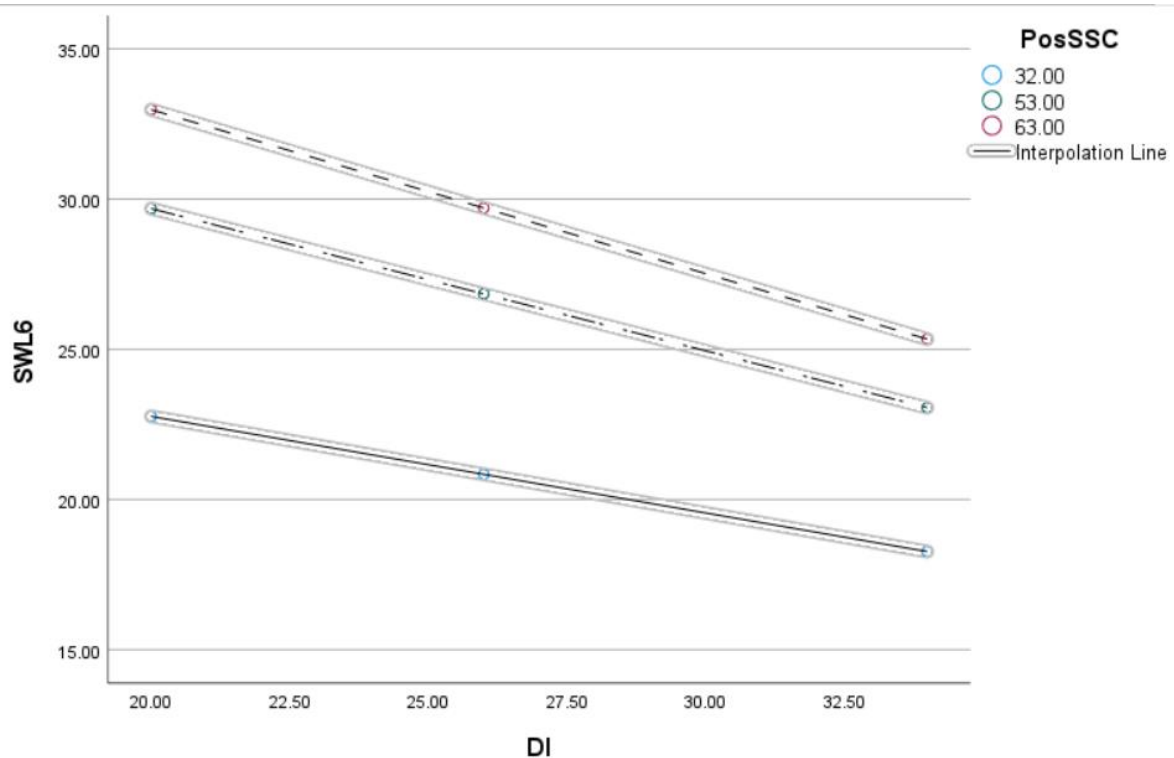


Figure 1: Graph illustrating the interaction between disability impact (DI) and Life satisfaction (SWL6) at the 25th, 50th and 75th percentile of scores on Positive Sexual Self Concept (PosSSC).

Discussion

The current study examined the relationship between sexual self-concept and life satisfaction among individuals with cerebral palsy and spina bifida. Sexual self-concept as a moderating variable between the impact of disability and life satisfaction was explored. Research has shown that impact of disability negatively correlates with life satisfaction and sexual self-concept.³⁸ However, positive sexual self-concept has been correlated with more life satisfaction.³⁹ Findings from this study along with the strengths-based perspective taken by counselors of individuals with disabilities,⁴⁰ suggest the need for cultivating positive sexual self-concept in individuals with disabilities to contribute to life satisfaction.

Clinical Implications

The present study emphasizes the importance of working with individuals with disabilities on their social, romantic, and sexual lives to help improve sexual self-esteem, optimism, and efficacy and to reduce anxiety in this area. Satisfaction with life was found to increase among individuals with disabilities when there was also an increase in sexual self-concept; this finding indicates that counselors and other professionals working with individuals with disabilities should work to cultivate positive sexual self-concept. The development of sexual self-concept is a typical task of the adolescent period of life,⁴¹ yet one often denied for individuals with disabilities. Research has found that positive sexual self-concept can be fostered through talking about sex positively,⁴² and having opportunities for sexual and other relationships.⁴³ In work with individuals with disabilities, we can broach the topic of sexual health as well as empower clients to seek out social opportunities and see themselves as sexual beings. Sexual health is an infrequently broached topic in counseling and education and even more so for people with disabilities; being willing to do so as a service provider can impact sexual self-concept, and sexual health, despite disability impact.

³⁸ Victor Moin, Ilana Duvdevany, and Daniela Mazor, "Sexual Identity, Body Image and Life Satisfaction among Women with and without Physical Disability," *Sexuality and Disability* 27, no. 2 (2009): 83-95.

³⁹ Ngairé Donaghue, "Body Satisfaction, Sexual Self-Schemas and Subjective Well-being in Women," *Body Image* 6, no. 1 (January 2009): 37-42.

⁴⁰ Wright, *Physical Disability*.

⁴¹ Rostosky, Dekhtyar, Cupp, and Anderman, 278.

⁴² Snell, "Measuring Sexual Self-Concept."

⁴³ Emily Impett and Deborah Tolman, "Late Adolescent Girls' Sexual Experiences and Sexual Satisfaction," *Journal of Adolescent Research* 21, no. 6 (2006): 628-646.

Limitations

This study looked at the impact of sexual self-concept on life satisfaction and as a moderator of disability impact. Given the nature of the study, there are a number of limitations that must be considered. First, the online survey design limited access only to those who received the link to the study and had access to computer and the internet. This limits the generalizability of the findings. In addition, the study's focus was on individuals with spina bifida and cerebral palsy, which could limit generalizability to other populations of people with disabilities. The nature of the topic of sexuality is also a study limitation; it is not uncommon to find bias in sexuality research and those who are willing to participate in such a study may already have a positive attitude toward sexuality as well as their own sexual selves,⁴⁴ also limiting generalizability. Finally, all scales in the study were self-report measures; this can impact the scientific measurement of the constructs. The results of this study should be interpreted with caution; causality should not be assumed from the data, though many of the correlations support past research findings.

Future Directions

Future research should examine the construct of sexual self-concept; the measure used in the current study was not used in its entirety and more qualitative research is needed to truly define the construct. Given that sexual self-concept did correlate with life satisfaction despite impact of disability, future studies on how sexual self-concept can be cultivated, particularly among adolescents with disabilities, are needed. Future research could also explore the moderating impact of sexual self-concept among other populations of individuals with disabilities.

Conclusion

This study contributes to the current research on sexual health and disability, and the impact of sexual self-concept on life satisfaction. This study explored the variances in the relationships among disability impact, sexual self-concept and life satisfaction and found that sexual self-concept significantly correlated with life satisfaction at low, medium, and high levels of impact of disability. This suggests that practitioners and service providers can help cultivate more positive sexual self-concept in individuals with disabilities to promote positive measure of this construct and improve life satisfaction.

⁴⁴ Strassberg and Lowe, "Volunteer Bias in Sexuality Research," *Archives of Sexual Behavior* 24, no. 4 (August 1995): 369.

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Intersections of Gender, Race, and Disability in the School to Prison Pipeline

Anna Clements¹

Introduction

The school to prison pipeline is a well-documented trend. Because of policies and attitudes in the United States, Black and brown students are disproportionately punished in schools and dealt harsher and more exclusionary punishments than white students, which leads them in the direction of incarceration.² This problem is multifaceted and intersectional; individuals who are multiply marginalized often face intersectional oppression within this pipeline, increasing the likelihood of adverse experiences. Black, Latinx, and Native American students with disabilities (particularly cognitive and psychosocial disabilities) are suspended or issued other exclusionary punishments at disproportionate rates. Experiencing exclusionary punishment is a predictor of incarceration.³ Thus, the special education to prison pipeline is a noteworthy facet of the school to prison pipeline, which disability policy ought to address.

Meanwhile, policy and disability rights groups are showing a growing concern over the prevalence of sexual and other gender violence that people with cognitive and psychosocial disabilities experience. The CDC's webpage on Sexual Violence and Intimate Partner Violence Among People with Disabilities states that an estimated 39% of females who experience rape, and 24% of men who experience sexual violence other than rape, had a disability at the time when they were victimized.⁴ This is disproportionate for both sexes; the CDC estimates that one in four women (25%) and one in five men (20%) has a disability.⁵

Currently, there is a dearth of research examining the relationship between these two trends, although they are logically and sociologically interrelated. Incarceration makes people more vulnerable to sexual and other gender violence. In my upcoming dissertation, I intend to

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² Roey Ahram, Catherine Kramarczuk Voulgarides, and Rebecca A. Cruz, "Understanding Disability: High-Quality Evidence in Research on Special Education Disproportionality," *Review of Research in Education* 45, no. 1 (March 2021): 311–45.

³ Charles Bell, "Special Needs Under Siege: From Classrooms to Incarceration" *Sociology Compass* 10 (2016): 698-705.

⁴ U.S. Department of Health and Human Services. Centers for Disease Control and Prevention. Sexual Violence and Intimate Partner Violence Among People With Disabilities. 2020, <https://www.cdc.gov/violenceprevention/intimatepartnerviolence/index.html>

⁵ National Center on Birth Defects and Developmental Disabilities. Centers for Disease Control and Prevention. Disability Impacts All of Us. 2020, <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

explore these relationships in greater depth; here, I will lay the groundwork to describe the basis of my argument that more attention is needed to evaluate the special education to prison pipeline and examine how this pipeline relates to trends of sexual and other gender violence that people with disabilities experience and evaluate the role that disability policy plays in this relationship.

A Multifaceted Problem: Components (an overview)

Before describing the relationships that I theorize, it is essential to break down their components. In this section, I provide a brief description of each of the phenomena central to the overall system of oppression that exists based on the intersection of racism, misogyny, and ableism, and the gender violence that this system facilitates.

Gender Violence

The term gender violence is not the same as sexual violence, nor is it the same as violence against women, although it incorporates both. Gender violence depends on cultural constructions of gender—gender roles and sexual stereotypes—which we begin to internalize during childhood.⁶ Albeit gender does not exist on its own; as it intersects with other identity components, the violence and harassment that are associated with gender interact with other forms of identity-based oppression. This can create conditions in which intersectional harassment takes place outside of traditional gender, racial, or disability harassment, making it difficult for institutions to respond through traditional mechanisms.

The CDC defines and describes gender violence in a way that encapsulates its complexity: Gender-based violence (GBV) is any form of violence against an individual based on biological sex, gender identity or expression, or perceived adherence to socially-defined expectations of what it means to be man or woman, boy or girl. This includes physical, sexual, and psychological abuse; threats; coercion; arbitrary deprivation of liberty; and economic deprivation, whether occurring in public or private life. GBV is rooted in gender-related power differences.⁷

Thus gender violence is not analogous to violence against women, as it is more complex, and takes into account the diversity of gender identity and gender expression. Anita Hill elaborates

⁶ Miguel Lorente Acosta, “Gender-based violence during the pandemic and lockdown,” *Spanish Journal of Legal Medicine* 46, no. 3 (2020): 139-145; M. Olsson, Martiny, S. E. Does Exposure to Counterstereotypical Role Models Influence Girls' and Women's Gender Stereotypes and Career Choices? A Review of Social Psychological Research. *Frontiers in Psychology* 9 (2018).

⁷ Global Health. Center for Disease Control and Prevention. Ending Gender-based Violence Globally. 2021, <https://www.cdc.gov/globalhealth/topics/gbv/index.html>

on the insidious, systemic nature of gender violence, and advocates a holistic approach to dismantling it:

The only way to address the troubling and persistent issue of gender violence and abuse is to take it apart and look at it step-by-step—where it comes from, how it builds—and thus understand how it's perpetuated within our culture and existing systems, or even in the language we use for it... And we also need to see how identity factors, including race, class, and sexual identity, can influence folks' experience with it.⁸

Disability is, of course, another identity component that influences folks' experience with gender violence—or rather, ableism and societal perceptions of disability influence how disabled people experience gender and gender violence.

Racial Inequities in Special Education

Often, discussions on race and special education focus on disproportionality. Cruz and Rodl define special education disproportionality as “the extent to which membership in a given group, such as gender, race/ethnicity, or socioeconomic strata, differentially affects the probability of being labeled as having a disability and placed in special education.”⁹ In their integrative literature review, they evaluate the methodologies used in twenty-six of the most prominent recent studies on disproportionality in special education, all of which are quantitative. The results of this review show that bivariate analyses of special education identification by race generally reveal disproportionality, with more Black than white students labeled as emotionally or intellectually disabled (and with mixed or less distinct results for Latinx or Asian students); however, multivariate analyses that include socioeconomic status and pre-academic knowledge are mixed, and sometimes indicate that Black students are underrepresented in special education.¹⁰

In 1968, education researcher Lloyd Dunn pioneered the argument that most special education programs should be integrated with mainstream classrooms, on the basis that as with racially segregated schools, segregating students with disabilities into separate classrooms and schools is likely to have a negative effect on their learning potential. Dunn states that schools' practices of hastily evaluating students, labeling them as disabled, and then placing them in separate special education classes “has resulted in digging the educational graves of many

⁸ Anita Hill, *Believing: Our Thirty-Year Journey to End Gender Violence* (New York: Viking, 2021), 11.

⁹ Rebecca A. Cruz and Janelle E. Rodl, “An Integrative Synthesis of Literature on Disproportionality in Special Education” *The Journal of Special Education* 52, no. 1 (May 2018): 50.

¹⁰ *Ibid*, 58-59.

racially and/or economically disadvantaged children.”¹¹ Based on a 1966 study by Rosenthal and Jacobson, in which some students in a classroom were arbitrarily labeled “rapid learners” and then demonstrated superior academic performance compared to their classmates over the following year, Dunn surmises that the inverse must be true for students labeled intellectually impaired. Although he examines segregation based on race and on special education status as parallel to one another throughout most of his argument, he predicts that someday the Supreme Court might disallow self-contained special education classes, on the basis that by serving primarily students of color and students of low socioeconomic status, they perpetuate racial segregation in practice.¹² More than fifty years later, policymakers still are failing to acknowledge the intersectional effects of disability policy, and the ways in which they facilitate racial inequities.

Sullivan and Bal (2013) describe some of the processes and factors that feed into disability identification. They determine that socioeconomic status (operationalized by coding for whether the student receives free or reduced-price lunch) and English proficiency, along with race, positively predict special education identification.¹³ They also state that “this disproportionality may result from cognitive sequelae of poverty; differential treatment of poor students in identification process; or differential opportunity to learn in a racially and economically stratified society.”¹⁴ Compared with white students, they determine that Black students are more likely to be identified as needing special education services overall (as is consistent with previous literature), but less likely to be identified with specific, low-incidence disabilities.¹⁵

Clearly, the overrepresentation of students of color, particularly Black students, in special education is an issue that scholars, educators, and policymakers in the United States have been discussing for decades. However, more recently, the issue of Black and other students of color being underrepresented in special education has also entered the discussion. Scholars argue that based on structural inequalities such as (but not limited to) higher levels of poverty, higher incidence of unmet medical needs, higher exposure to environmental toxins, and underfunded schools with less capacity to identify individual students’ needs, Black and Latinx students are

¹¹Lloyd M. Dunn, “Special Education for the Mildly Retarded: Is Much of it Justifiable?” *Exceptional Children* Volume 23 (1968): 9.

¹² *Ibid.*, 7-9.

¹³Amanda Sullivan and Aydin Bal, “Disproportionality in Special Education: Effects of Individual and School Variables on Disability Risk” *Exceptional Children* 79, no. 4 (2013): 488.

¹⁴ *Ibid.*, 490.

¹⁵ *Ibid.*, 482-483.

actually underrepresented in special education in terms of the proportion of students who have special needs receiving school-based accommodations for those needs. This position is based on the premise that while Black children, and to a lesser extent, Latinx children may be identified as needing special education services at higher rates than white children, this in itself is not the main problem; based on the social conditions that create disability, proponents of this position argue that Black and Latinx children should be identified at higher rates than they currently are.¹⁶ Neglecting to identify students for special education can negatively affect the students' academic success; recent studies have shown receipt of special education services to positively impact both academic achievement in school as well as post-high school opportunities.¹⁷

I argue that disproportionality would not be an issue if schools provided disability accommodations in a non-ableist way. If identifying a student as disabled were not perceived as either causing stigma (in cases where individualized special education services are scant, and students receiving services are separated from their peers—placed in disability ghettos, effectively) or as giving the student an unfair advantage (in situations where special education services are strong), but simply understood to be a fair response to ableist structures, then there would be no reason to misuse disability labels in racist ways. Stigmas surrounding discussions of racism and disability prevent policymakers from correctly identifying and addressing the problems at hand.

Race and the Special Ed to Prison Pipeline

Researchers and policymakers are beginning to recognize how racial inequities in schools' responses to disability funnels people into the school to prison pipeline. However, the complex intersections of problems and identity components are often neglected, as scholars and organizations focus on separate aspects of the system, and not their interactions. For instance, race and disability as predictors of incarceration are often discussed separately. On its webpage titled "The School-to-Prison Pipeline," the American Civil Liberties Union states:

The ACLU is committed to challenging the "school-to-prison pipeline," a disturbing national trend wherein children are funneled out of public schools and into the juvenile and criminal

¹⁶ Paul L. Morgan, George Farkas, Marianne M. Hillemeier, Richard Mattison, Steve Maczuga, Hui Li, and Michael Cook, "Minorities Are Disproportionately Underrepresented in Special Education: Longitudinal Evidence Across Five Disability Conditions," *Educational Researcher* 44, no. 5 (2015): 269; Todd E. Elder, David N. Figlio, Scott A. Imberman, and Claudia L. Persico, "School Segregation and Racial Gaps in Special Education Identification. National Bureau of Economic Research," *Working Paper* 25829. 7

¹⁷ *Ibid*, 7

justice systems. Many of these children have learning disabilities or histories of poverty, abuse, or neglect, and would benefit from additional educational and counseling services. Instead, they are isolated, punished, and pushed out.¹⁸

The authors cite inadequate resources in public schools, increasing reliance on police in schools, and zero-tolerance policies as some of the root causes behind this trend; they state that the lack of due process particularly affects students with disabilities¹⁹. These students' behaviors might relate to their disabilities, and might be easily addressed through institutional accommodations, were there more flexibility and creativity in the ways in which schools respond. What is missing from this narrative is a consideration of the roles of race and racism.

In a 2012 report, Losen and Gillespie found that nationally, during the 2009-2010 school year, 5% of all white students were suspended at least once; 17% of all Black students; over 13% of students with disabilities of all races; and 25% of Black students with disabilities were suspended from school at least one time²⁰. Wald and Losen (2003) found that the greatest predictor of incarceration among Black girls is the experience of exclusionary punishment (such as suspension or expulsion) in middle school.²¹ Sociologist Charles Bell responds to these statistics in a way that concisely captures their irony:

These findings are particularly troubling because federal law mandates an individualized education plan (IEP) for students with disabilities. The IEP is designed to create a collaborative support system that works to ensure students with disabilities receive the proper services. Considering the additional support, it would seem reasonable to expect school suspension rates among students with disabilities to be less than their non-disabled counterparts.²²

Special education policy and programming is designed to support students with disabilities. But it is not designed in a way that takes this country's racist past and present into consideration.

¹⁸ American Civil Liberties Union, "School-to-Prison Pipeline" American Civil Liberties Union, accessed February 15, 2022,

<https://www.aclu.org/issues/juvenile-justice/school-prison-pipeline/school-prison-pipeline#:~:text=The%20ACLU%20is%20committed%20to,juvenile%20and%20criminal%20justice%20systems.>

¹⁹ Ibid.

²⁰ Daniel J. Losen and Jonathan Gillespie, "Opportunities Suspended: The Disparate Impact of Disciplinary Exclusion from School," The Center for Civil Rights Remedies at The Civil Rights Project, UCLA (2020), 6-7.

²¹ Wald, J., & Losen, D. J. Defining and redirecting a school-to-prison pipeline.

New Directions for Youth Development. 99 (2003) pp. 9-15. <https://doi.org/10.1002/yd.51>

²² Charles Bell, "Special Needs Under Siege," *Sociology Compass* 10, no. 8 (2016): 701.

A Multifaceted Problem: How the Components are Interrelated

Bell (2016) cites statistics from the US Department of Education illustrating that between a quarter and a third of African American, Latinx, and mixed-race incarcerated adults have cognitive disabilities; he takes data from school records to show that African American, Native American, and Latinx students with disabilities are suspended at rates far above national averages.²³ While much of the extant research on the school to prison pipeline focuses on Black and brown boys, Black girls are also affected. Black girls with disabilities are suspended at higher rates than other girls,²⁴ and girls with mental health disabilities comprise over 80% of girls in the juvenile legal system.²⁵

Sexual victimization is common within the juvenile legal system, though its exact prevalence is unknown due to issues with underreporting. Koski et al. calculate that over 6% of adolescents in New York juvenile detention facilities experienced sexual contact from staff at the facilities (250).²⁶ Incarcerating youth with disabilities is contributing factor to the prevalence of sexual and other gender violence to which people with disabilities are subjected.

Basile et al. analyzed data from the 2010 administration of the National Intimate Partner and Sexual Violence Survey (NISVS) and found that both women and men with disabilities experience sexual and other gender-based violence at slightly higher rates than those without disabilities.²⁷ However, they acknowledge that this survey does not include responses from people living in institutions such as assisted living facilities or prison.²⁸ More research is needed in this area.

Too often, research on racism and mass incarceration, and research on the experiences of people with disabilities, are completed far away from one another; the policy spheres remain separate as well. But if racial inequities in special education service provision contribute to a greater likelihood of incarceration among people with disabilities, and incarceration makes people with disabilities more vulnerable to gender violence, then it is imperative that disability policy address the roots of the problem in concrete, effective ways.

²³ Ibid., p. 703

²⁴ Monique Morris, *Pushout: The Criminalization of Black Girls in Schools* (New York: The New Press, 2016) p. 57

²⁵ Ibid, 152

²⁶ Susan V. Koski, D. Bowers, and, S.E. Costanza, "State and Institutional Correlates of Reported Victimization and Consensual Sexual Activity in Juvenile Correctional Facilities," *Child Adolescent Soc Work* 35 (2018): 250.

²⁷ Basile, Kathleen C., Matthew J. Breiding, and Sharon G. Smith, "Disability and Risk of Recent Sexual Violence in the United States." *American Journal of Public Health* 106, no. 5 (2016): 929.

²⁸ Ibid, 932.

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Doe as Thou Wouldst be Done By: Relief Responses to Mental Illness in Puritan New England¹

Rebecca Farias²

New England Puritans envisioned the ideal community as built on the virtues of sympathy and reciprocity towards the weakest among them, including, in theory, people with mental illnesses and other disabilities. Without good works of charity in action, their civil society would not stand. John Winthrop's *A Model of Christian Charity*, a then little-known speech which came to encapsulate the theocratic goals of the Puritan diaspora to New England, championed "a sensibleness and sympathy of each other's conditions" which would "strengthen, defend, preserve and comfort the other."³ Winthrop's overall "model" framed a worldview of reciprocal giving based on prayer- and prayer translated into charitable action. Elaborating on the biblical sentiment of the Golden Rule, "Doe as thou wouldst be done by," the English Puritan minister Robert Bolton advised his congregation: "In a fellow-feeling real conceit, put thy self into the place, and impartially put on the person of the party with whom thou art to deal."⁴

Although folk remedy and theology pervaded their worldview, the Puritan response to mental illness did not tend to frame witchcraft and the supernatural elements as the primary cause of mental illness among community members. Witchcraft historian John Demos even argued that "numerous and varied forms of evidence suggest that insanity was recognized, appear."⁵ While Puritan life was peppered with supernatural explanations, the issue of mental illness was regarded with a special degree of rationality, caution, and care. This rational response stems from the need for disabled Puritans to define and assert their disability in order to receive aid or exemption from expected contributions, such as paying taxes or attending public worship.

While the Puritan philosophy of charity extended to all, in theory, variables based on cultural assumptions about age, gender, socioeconomic status, and criminality, complicated

¹ Excerpt from a Thesis presented for a Master's in History at Providence College to: Dr. Jeffrey Johnson, Director of History Program. Mentored by Dr. Adrian Weimer, Primary Advisor. Secondary Advisors: Drs. Steven Smith and Edward Andrews.

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³ John Winthrop, "A Modell of Christian Charity," in *Boston: Collections of the Massachusetts Historical Society*, 1838, 3rd series, 7:31-48.

⁴ Robert Bolton, *Some General Directions for a Comfortable Walking with God, Delivered in the Lecture at Kettering in Northamptonshire*, (Early English Books Online:1626), 207.

⁵ John Demos, *Entertaining Satan: Witchcraft and the Culture of Early New England*, (New York: Oxford, 1982), 167.

care for the afflicted and insane by changing the ways in which people viewed the severity and legitimacy of their illness. The case studies in this thesis originate from county and colony court records of welfare petitions from Massachusetts, Rhode Island, and Connecticut. Each case of mental illness is unique as the subjects themselves, but an analysis using the following questions yields patterns in relief responses, which may help reveal how Puritans conceptualized and then treated afflicted people:

1. Is the condition viewed as a permanent part of the person's temperament, or was it due to temporary or external factors such as poverty or bewitchment? Do they have a chance of rehabilitation?
2. Is the illness supernatural, natural, or caused by a combination of these attributes?
3. To what extent is the afflicted person presented as a strain on family and community resources? Can they provide for their own care and finances? Have they exhibited a pattern of dangerous or criminally disruptive behavior?

In Puritan New England, boundaries between different types of mental illnesses were fluid. New World Puritans inherited an English view of mental illness that was just beginning to delineate from the medieval conception of insanity as a moral failure demarcating unworthiness of the sufferer. Broadly, such theories were posited by Catholic theologians and classical philosophers, framing mental illness as a sign of losing a personal struggle with God.⁶ Popular literature began to explore symptoms, causes, and effects of mental illness during the Renaissance and Enlightenment. Meanwhile, physicians gradually launched humanistic methods of scientific inquiry in order to begin to medicalize, and therefore confront and normalize mental illness.⁷

In all aspects of Puritan society, including support for those with temporary and permanent illness, disability, or poverty, the family, not physicians or the government, was always intended to be the first line of defense to protect the weak. An emotionally-charged example of the complexities of family care comes in the repeat petitions of John Heydon, resident of Braintree and Dorchester, Massachusetts. Heydon and his wife Susanna appear in

⁶ Michel Foucault, *Madness and Civilization: A History of Insanity in the Age of Reason*, (New York: Random House, 1965).

⁷ The medicalization of mental illness did not begin to gain widespread scientific acceptance until the mid-1800s, and popular acceptance did not immediately follow, of course.

the Massachusetts records multiple times over a period of seven years, each with the same request:

In answer to the petition of John Heydon, for some relief in respect of his distracted or possessed child, it is ordered, that the petitioner shall have five pounds given to him by the country, to be payed by the auditor general out of the revenues that cometh from the imposition layed upon by wines.⁸

The petitioner always describes John's child, Joseph, as "distracted or possessed," meaning that although the cause of the mental illness could not be determined as supernatural, natural, or even demonic, the child was still worthy of assistance, having come from a poor family in good standing with the town.

Additionally, the "revenues that cometh from the imposition layed upon by wines" are drawn from taxpayer dollars, so John's child was supported by community monies. John and Joseph's story does not end there, however: when John died in 1681/2, he left a detailed will, as was customary in New England families. John himself perished from some unknown "sickness" that caused "weakness" which inhibited his ability to work, and his family cared for him until he died. Significantly, John willed his entire estate to his mentally ill son Joseph, which would be used for Joseph's care by Susanna, or "maintenance," until the end of his life. Despite his permanent infirmity, Joseph received an equal share in his father's estate as his brothers, who were not described as mentally ill or disabled.⁹

The recurring description of Joseph as "the distracted or possessed child" throughout the welfare petitions also indicates a certain degree of infantilization on part of the family and the state, perhaps invoked by the dependency caused by his condition. However, this characterization would require further study and a larger data set before drawing any conclusions about how the Puritans conceptualized intellectual development in mentally ill children.¹⁰

However, "problem families" who reissued requests for welfare without attempting to work or who presented other chronic legal issues gleaned less sympathy from general courts

⁸ *Records of the Governor and Company of Massachusetts Bay in New England, Vol. 3, 1644-1657*, ed. Nathaniel Bradstreet Shurtleff, (UMass Amherst Libraries, 1853), 140, <https://archive.org/details/recordsofgoverno03mass/page/70/mode/2up>.

⁹ Noah Tutak, "John Heydon of Braintree-Dorchester," *Geni.com*, <https://www.geni.com/people/John-Hayden-of-Dorchester-Braintree/600000008300553043>

¹⁰ Joseph lived to be 59 years old so was certainly not a child when he died.

and from disapproving neighbors. Sometimes mental illness was involved in cases of problem poor families, but often the mental illness was simply a colluding factor in a case of poverty, child abuse, spousal infidelity, or “work-shy” adults who refused to contribute to the community or even faked disabilities- issues that all had to be dealt with separately. The following examples highlight the stark contrast between Puritan welfare responses to two disruptive families: the Leavitt, whose afflicted son Israel presented a short-term and low-impact problem, and the Balls, whose mentally unstable matriarch, Elizabeth, exhibited a stubborn pattern of physical and financial abuse and neglect.

Born in 1680 to Israel Leavitt and Lydia Hall, Hingham, Massachusetts resident Israel Leavitt shared the household with eight siblings.¹¹ Despite the unusually high number of children, however, Leavitt does not appear in the archives under a welfare petition. Rather, the ecclesiastical records instead show a dispute over compulsory church attendance resolved by Leavitt and his family’s assertion of logical exemption due to Israel’s “fits.”

His fits were a permanent affliction that presented minor social complications, easily resolved by his agency over asserting his own condition and bodily autonomy, if not for the hassle of his family providing testimony as to the legitimacy of his absence. Nowhere in the record indicates that Israel’s fits became a financial or social burden beyond this singular inconvenience. The Massachusetts General Court summoned Suffolk resident Deacon Thomas Loring to testify on behalf of Israel’s excused absence from worship; someone had filed a complaint that Israel had missed several religious services, which was against the law without an acceptable excuse:

Thomas Loring aged 32 years or therabout being summoned to give an [?] against Israill Lovitt for not attending the publick worship of god so sayeth that in [?] informed the granjury against Isarill Lovit in this mator- Tho I have not seen him lately in the meetinghouse to my knowledge yet I do say that I have seen him by the first of the meeting house on the Lords day and asked him the Reson of his not going, and he replyed that he dare not by Reson of his fits lest he make a disturbance - - - and further saith not

Constable John Smith

September 1694.

¹¹ “Israel Leavitt,” *Geni.com*, <https://www.geni.com/people/Israel-Leavitt/6000000003132974677>.

89 c: [?] Hall aged 31 years [?] about doings Being Summoned to give in [?] against Isral Leavitt for not attending the publick worship of god and [?] and sayeth that I [?] informed the granjury against Israel Levitt in this mater [wither? Neither?] can I say thatyou [absolve?] so Israel Levitt doth not [?] Upon your Publick worship of god on the Lords Day and further saith not [?]

John Smith Sept 29, 1664.

Sarah and Josiah Leavitt, two of Israel's siblings, were made to provide a deposition on his behalf, which appeared to satisfy the court. Josiah, his mother, and his father all signed the document:

This may Satisfy any whom or may Come that Written do upon our knowledge humbly testify that Issrael Leavett of Hingham, who is now ... and upon publicke worship on Sabbath days is often taken with fitts This may Satisfy any whom or may Come that who is now ... and upon publicke worship on Sabbath days is often taken with fitts . . . supposed he be falling.¹²

According to Corenelia Hughes Dayton, the main difference between New England Puritan courts and English courts was that citizens interacted directly with the legal system; there were no lawyers to intercede on their behalf. In the case of Israel Leavitt, his attempts to clear his name were steeped in an assumption of his inherent piety- he would not miss worship without the excuse of his illness, and his intention- to keep the worship peaceful by removing himself- was pure. Therefore, Israel, through the authority of Constable John Smith, utilized Deacon Loring and his family as character witnesses to legal trouble and the stigma of skipping the ceremony. Thus, Israel and his family asserted his right to abstain, granting legitimacy to his illness by petitioning for social acceptance. It is unknown if he was granted permission to skip services, but with his disability designation does come a sort of assumed decreased responsibility. His disability was defined by what he should not or could not do, as opposed to what he could do. In fact, Israel legally held the right to refuse to attend service because of his condition, a law that was invoked to codify the autonomy of the disabled inhabitants of Puritan New England:

Massachusetts Body of Liberties of 1641: No man shall be punished for not appearing ator before any Civill Assembly, Court, Councill, Magistrate, or Officer, nor for the omission of any office or service, if he shall be necessarily hindred by any apparent Act or providence of God,

¹² *Records of the Governor and Company of Massachusetts Bay in New England, Vol. 10, Ecclesiastical, 1679-1739*, 89a, <https://archive.org/details/recordsofgoverno05mass/page/62/mode/2uphttps://www.familysearch.org/ark:/61903/3:1:3Q9M-C9Y5-S38P?cat=1055547>

which he could neither foresee nor avoid. Provided that this law shall not prejudice any person of his just cost or damage, in any civil action.)¹³

Unfortunately, families whose mental illnesses presented as long-term poverty, violence, or criminality could not be rectified with a simple petition or protectionary clause. In the case of Watertown wife and mother Elizabeth Ball, her antisocial behavior strained the authorities' sympathy so much that they eventually resorted to punishment and correction rather than remediation, as Israel Leavitt reached. In Elizabeth's case, the only suitable answer was family separation.

Elizabeth Fiske Ball was born in 1667/1668 in Watertown, Middlesex County, Massachusetts. She married weaver and husbandman James Ball in 1693/1694. Elizabeth gave birth to eight children over a period of about 12 years (records may vary due to double dating), and the Balls were unable to accommodate for their needs. Elizabeth's "disturbed mind" contributed directly to their destitution. Her mother, Elizabeth Fry, had suffered from a similar ailment and had been assigned a "keeper," or legal guardian, back in Norwich, England.

Elizabeth's marriage to James suffered from her volatile behavior; in December 1656, selectman arranged for foster parents to remove and rehome some of her remaining children. Breaking up families was a regrettable course of action and a last resort aimed at protection of the children, and the selectman probably would not have made this decision had it not been for Elizabeth's allegations of physical and verbal abuse against her husband and other townspeople. In 1657 and 1659, even after the separation of her family, Elizabeth continued her behavior and was presented to the Middlesex County Court for "several disorderly carriages against both her husband and her neighbors."¹⁴ As Burton writes of the power of mislead passions, Puritans understood cruelty and anger as unchecked forces for evil: "The mind most effectually works upon the body, producing by his passions and perturbations miraculous alterations, as melancholy, despair, and diseases."¹⁵ Elizabeth's emotions affected not only her mental clarity, but also the integrity of her marriage and family.

She pleaded "hard usage" against her neighbors, meaning that they had given her no other choice but to react with vitriol. She argued that "her husband neglects her in suffering to want necessary supplies and also did kick her." Elizabeth had been witnessed "scratching and

¹³ *Massachusetts Body of Liberties of 1641*, page 261, Section 4.

¹⁴ Thompson, *Divided*, 108.

¹⁵ Burton, *Melancholy*, Subsect 1.

punching” her own father’s face. Despite her ability to present her case in court, Elizabeth and three older children were sent away to live with grandparents, while an infant child went to live with an aunt. However, John remained responsible for the financial welfare of his children and wife, to whom he was still legally married. Elizabeth was treated with sympathy following the agreement: “if she be brought to be comfortably enjoyed as a wife fit to live [with], she may be brought to live with her husband again.” In the meantime, if she refused to earn her keep in her new home, “she must expect to be sent to the house of correction.” They never reunited. She died in the early 1690s, and John later remarried; John perished in King Phillip’s War after relocating to the settler town of Lancaster.¹⁶

As a member of a notoriously problematic family, Puritan officials dealt with Elizabeth more harshly than if she had suffered benignly with mental illness. However, the affliction contributed to her violent and antisocial behavior, so they separated her from some of her children and from her husband in order to protect all parties and preserve the peace in Watertown. Although Elizabeth had the chance to assert herself in court, she nonetheless succumbed to gendered expectations about living as a proper wife and mother, which the court determined that she was legally incapable of fulfilling. Worse yet, her decision to remain idle while able-bodied forced Puritan authorities to intervene because she was not supporting herself, her family, or the community.

While it is tempting to conclude that Puritans were sympathetic towards the “virtuous” mentally ill and cruel towards the criminally insane, the archives show that such neat and linear categorization of disability is rarely the case. Just as early Anglo-American disability existed on a spectrum of symptoms, causes, functions, and public perceptions, so too did the treatment of mentally ill people vary in Puritan America based on social and economic variables. Much like people with mental illness today, afflicted Puritans faced a variety of challenges when it came to securing care, asserting financial autonomy, and asserting their specialized and unique legal rights. However, unlike today, Puritans in the 1600s had no access to other welfare or medical institutions other than the family, the county, and the colony- each respective level providing a decreasing amount of care by their increase in distance from the individual afflicted person.

Studying early Puritan relief responses to mental illness before the onset of state-

¹⁶ Thompson, *Divided*, 108-109.

sponsored disability pensions during the American Revolutionary War can provide a glimpse into a world where family care was normalized above all other authorities- a world that no longer exists in the New England of today.

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Deaf Culture at the Intersection of History and Disability

James I. Deutsch¹

From June 24 through July 5, 1981, in recognition of the International Year of Disabled Persons, the Smithsonian Institution's Festival of American Folklife presented a pathbreaking program, *To Hear a Hand: Folklore and Folklife of the Deaf*. During the two weeks of the Festival, which took place on the National Mall of the United States in Washington, D.C., Deaf participants—through the richness of American Sign Language and the help of interpreters—made their personal histories accessible to tens of thousands of visitors, most of them hearing. They told stories and jokes, performed their signlore, presented their traditions, and discussed their experiences of growing up Deaf. The program allowed participants to share their perspectives on living in a hearing world, where their culture still often passes unnoticed and where members of the Deaf community must contend with many of the negative stereotypes associated with what many hearing people perceive as a “disability.”

The Festival program in 1981 powerfully contradicted those negative stereotypes not only by making clear that Deafness for members of the Deaf community is a culture, not a disability, but also by highlighting the strengths, resourcefulness, and achievements of that culture. By all accounts, this program was a landmark event for the Deaf community in the United States. It brought together—on a national stage, perhaps for the first time—Deaf participants and visitors, some of whom would go on to play leading roles in the Deaf President Now protest at Gallaudet University in 1988 and in the Disability Rights Movement, which helped to ensure the passage and signing of the Americans with Disabilities Act (ADA), signed into law on July 26, 1990, by President George H.W. Bush.

This article seeks to demonstrate the historical significance and lasting legacies of the 1981 Folklife Festival event. Primary source materials include retrospective conversations with the principal organizers, as well as audio recordings—many of which have not been heard in more than thirty years—from the event itself. Digitized in 2018 from decaying audiocassettes, these recordings illustrate some of the ways in which the Smithsonian Institution brought greater access and inclusion to Deaf Culture at a pivotal intersection in the movement's history.

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The Festival of American Folklife is often referred to as “a museum without walls” or “an outdoor museum.” Under the aegis of the Smithsonian Institution—the nation’s largest museum and research complex—the Folklife Festival began in 1967 in part to honor some of the nation’s finest practitioners and bearers of intangible cultural heritage. In the fifty-plus years since, the Festival has managed to celebrate the traditional culture of roughly one hundred different countries, every U.S. state, and a wide variety of occupational and religious groups. Its name changed to Smithsonian Folklife Festival in 1998 to reflect its increasingly international scope beyond “American folklife.”

The Folklife Festival is easily the most prominent and popular event taking place each year in Washington, D.C., within the boundaries of the National Mall of the United States, which is administered by the U.S. National Park Service—the same federal agency that maintains and preserves Grand Canyon National Park, Yellowstone National Park, the Statue of Liberty National Monument, and many other special places in the United States. The National Mall is where Martin Luther King Jr. declared his dream in 1963, where large protest marches and demonstrations regularly take place (at least pre-pandemic), and where millions of people stood in below-freezing temperatures to watch the presidential inauguration of Barack Obama in 2009. With the U.S. Capitol on the eastern end, the Lincoln Memorial on the western end, the Washington Monument and National World War II Memorial in the center, and several museums of the Smithsonian Institution on both north and south, the National Mall is arguably the nation’s most important civic space. The Folklife Festival almost always takes place for a period of ten days during the week before and the week after the Fourth of July—American Independence Day—which is the nation’s most important civic holiday.

According to Festival legend, S. Dillon Ripley (the head of the Smithsonian Institution from 1964 to 1984) in 1966 told Ralph Rinzler (the Festival’s founding director) to “take the instruments out of their cases and let them sing”—meaning that the Folklife Festival should not only demonstrate the utility and vitality of the Smithsonian’s collections of musical instruments (most of which were locked inside museum exhibition cases and vitrines), but also present the vitality of diverse musicians and performers—and thus the vitality of their cultural heritage, both old and new. Ever since, the two primary goals of the Smithsonian Folklife Festival have been: 1) to strengthen and preserve this cultural heritage by presenting it on the National Mall in a respectful way; and 2) to promote mutual understanding between Festival participants and

Festival visitors through “cultural conversations,” in which Festival participants and visitors speak directly to each other in their own voices.

In achieving these goals, the Folklife Festival itself should be highly collaborative—with Smithsonian staff members contributing their expertise, based on years of experience in producing large public programs on the National Mall, but also utilizing and benefiting from the cultural-heritage research contributed by their partners from the countries and regions that are featured at the Folklife Festival. The objective is to promote cooperative learning, rather than to rely exclusively on Smithsonian expertise, which is more the norm for the exhibitions that are curated at the Smithsonian’s indoor museums.

The 1981 Festival program, *To Hear a Hand: Folklore and Folklife of the Deaf*, came to life through the synergy of several concurrent events. One was the pioneering research of Simon Carmel, who had been collecting examples of Deaf folklore for many years. As Carmel told me in April 2019, “I loved collecting both Deaf and hearing clean and dirty jokes and other stories for my private collection while I was working as a physicist for twenty years,” which led to his teaching a class on Deaf Culture and Deaf Folklore at Gallaudet University in fall 1977.²

Carmel also was giving lectures and conference presentations, including a session on Deaf folklore at the American Folklore Society’s annual meeting in 1980, which he had co-organized with Jo Radner, who was teaching folklore, Celtic studies, and English literature at American University. Radner had met Carmel through Stephanie Hall, one of Radner’s graduate students in folklore, whose grandfather, Percival Hall, was Gallaudet’s second president, and whose father and uncle were both members of Gallaudet’s faculty.

Jack Santino, a folklorist with the Smithsonian’s Office of Folklife Programs, also was aware of these activities and had proposed a program on Deaf Culture several times to Ralph Rinzler, the Festival’s founding director. As Santino recalled in April 2019, “at a staff meeting, out of the blue, Ralph said to me, ‘Why don’t you do a Deaf program for this year’s Festival? You’re always talking about it, so now’s your chance’ or words to that effect.” One impetus for Rinzler’s decision may have been that the United Nations had declared 1981 as the International Year of Disabled Persons.³

² Simon Carmel, email correspondence with the author, April 16, 2019.

³ Jack Santino, telephone conversation with author, April 15, 2019.

Santino and Rinzler hired Carmel and Radner in early 1981 to co-curate the program with assistance from Hall and others. By the time the Festival opened on June 24, 1981, they had arranged a multifaceted program with several elements. There were storytelling sessions and workshops, in which Deaf participants shared traditions of Deaf culture—including jokes, riddles, puns, and games. Session titles included “Deafness in a Hearing World,” “Deafness in the Family,” “Favorite Deaf Heroes,” “Legends in the Deaf Community,” and “Hazards of Being Deaf.” Also featured were performances by Studio 101, a Deaf acting company; presentations on “The Beauty and Poetry of American Sign Language (ASL),” which highlighted the richness of the language; classes for visitors in ASL; and an exhibition of practical devices from doorbell signals and wake-up alarms to modern telecommunications equipment.⁴

The result was narrative sessions, encounters on the Mall, and conversations that express much poignance. For instance, Don Pettingill, then director of adult education programs at Gallaudet University, carefully explained the three primary problems that Deaf people face in a hearing world.

- “Our deafness is invisible. If you meet us on the street, you won’t know we are Deaf.
- Deaf people really can’t hear. We need you to understand that.
- Hearing people, ordinary hearing person will never be able to understand 100 percent what it’s like to be Deaf. You can plug your ears, but you will never understand us.”⁵

Because building understanding between the Deaf and hearing communities was one of the program’s primary goals, Pettingill explained, “When I was growing up, I always felt that not many hearing people were educated about Deaf people. They do not know a lot and I felt very isolated. But nowadays, there are more people who know about Deaf people and they take sign language classes. It’s really a nationwide fad, and now people have better attitudes towards Deaf people today than when I was little. It’s a more positive feeling to be Deaf today, in the past there was great fear and revulsion and isolation, now there is great mingling.”⁶

⁴ The titles of these sessions come from log sheets of recordings at the 1981 Festival of American Folklife, held by the Ralph Rinzler Folklife Archives and Collections, Smithsonian Institution, Washington, D.C.

⁵ Don Pettingill—translated via ASL—in undated audio recording, from Festival of American Folklife, ca. June 1981, Ralph Rinzler Folklife Archives and Collections, Smithsonian Institution, Washington, D.C., transcribed by author and Abigail Hobart.

⁶ Don Pettingill—translated via ASL—in undated audio recording, from Festival of American Folklife, ca. June 1981, Ralph Rinzler Folklife Archives and Collections, Smithsonian Institution, Washington, D.C., transcribed by author and Abigail Hobart.

To describe this type of mingling, Pettingill provided some specific examples of how the Festival program was helping to promote mutual understanding: “I’ve grown up meeting hearing people, and I know that hearing people are afraid because they don’t know how to communicate with Deaf people, and I am scared to communicate too, we feel the same. After a while, hearing people share their real feelings with me about their fear of Deaf people. Yesterday, after the workshop, I was walking home along the Mall to get my car, I was walking with some things, spare ribs and so on. A girl went past me and waved, and I nodded at her. And she said, I’m a hearing person. I lipread that. I took out the paper and we were writing back and forth, it was a very nice experience. We did that until I got to my car and I said bye and she left, and we went our ways. It was very nice.”⁷

The Festival program on Deaf culture also facilitated the participation of audience members—many of whom were Deaf—to share their own stories about life in a hearing world. In one case, an audience member related a near-calamitous medical experience: “Hello, my name is Sandra. I fainted, was taken to the hospital. I woke up and the doctors said we’re going to give you a shot and surgery. I said that’s not me and started fighting, and asked for an interpreter and they said the room was too small, and I became wild and they finally brought in an interpreter. I said, you want the hearing person next to me, they’re ready for their shot and cesarean.”⁸ Another audience member described another problem when seeking medical attention: “My teacher said she had to go to the doctor one day. She wrote down on paper that she was deaf to the receptionist. She waited for a while, other people came in and left before her. She had been there for a few hours. She talked to the receptionist, who told her, “I was calling your name for hours but you didn’t show up. Oh, I forgot you’re deaf.”⁹

In retrospect, the timing of the Smithsonian event seems most propitious. As Stephanie Hall recalled in April 2019, “The Deaf culture performances and exhibits turned out to be a big hit at that festival. We were able to prove that Deaf culture could draw an audience.”¹⁰ Similarly, Jo Radner observed, also in April 2019, “It was a very interesting time to be involved with the

⁷ Don Pettingill—translated via ASL—in undated audio recording, from Festival of American Folklife, ca. June 1981, Ralph Rinzler Folklife Archives and Collections, Smithsonian Institution, Washington, D.C., transcribed by author and Abigail Hobart.

⁸ Sandra—translated via ASL—in undated audio recording, from Festival of American Folklife, ca. June 1981, Ralph Rinzler Folklife Archives and Collections, Smithsonian Institution, Washington, D.C., transcribed by author and Abigail Hobart.

⁹ Unidentified audience member—translated via ASL—in undated audio from Festival of American Folklife, ca. June 1981, Ralph Rinzler Folklife Archives and Collections, Smithsonian Institution, Washington, D.C., transcribed by author and Abigail Hobart.

¹⁰ Stephanie Hall, telephone conversation with author, April 15, 2019.

Deaf community. Deaf politics were just coming into their own.”¹¹ Moreover, as Brian Greenwald, professor of history and director of the Schuchman Deaf Documentary Center at Gallaudet, told me in April 2021, the Festival program took place the same year as the publication of Jack R. Gannon’s seminal 1981 book, *Deaf Heritage: A Narrative History of Deaf America*. “The Festival and the growing corpus of scholarship were part of a larger trend of surging outward pride, where stories, jokes, and other elements of Deaf culture were shared with the wider audience that was seldomly seen previously,” Greenwald explained. “As a Deaf child born to hearing parents, I grew up without access to stories about Deaf people and missed untold numbers of jokes and opportunities to learn about the history of Deaf people.” Although Greenwald did not attend the 1981 Festival, he noted how important those stories were at the time. “Stories are one of the most powerful tools we have as humans. They would come cascading later in my life as I found my way to the Deaf community.”¹²

One of Greenwald’s faculty colleagues, William Ennis, associate professor of history at Gallaudet, *was* at the Festival—as a twelve-year-old, watching his father Bill Ennis perform. “My father was a master storyteller,” Ennis told me in April 2021. “The way that he could weave so many details into his storytelling performances was something special. That is the essence of what Deaf stories are made of—not linear English words, but rather the masterful use of the whole body to provide a three-dimensional story. Those kinds of stories and American Sign Language are the backbone of Deaf culture.”¹³

When asked during the 1981 Festival if there might be another Deaf Culture program in the coming years, Rinzler replied, “I can’t answer that question right now until a whole bunch of us sit down and try to figure out what the shape of the Festival will be next year. But it seems very likely—now that we’ve gotten ourselves thinking about this kind of a program—there is every reason to assume that it will come back, if not next year, in two years or three years.”¹⁴

The same question was asked on one of the discussion stages, to which an unidentified panelist replied, “You stole the words right out of my mouth, well off my fingertips actually. For many years, Deaf people were not considered a cultural group. The focus was geared toward making Deaf people hearing people, and that’s impossible. Then sign language was accepted

¹¹ Jo Radner, telephone conversation with author, April 4, 2019.

¹² Brian Greenwald, email to author, April 1, 2021.

¹³ William Ennis, email to author, April 10, 2021.

¹⁴ Ralph Rinzler in undated video recording, from Festival of American Folklife, ca. July 1981, Ralph Rinzler Folklife Archives and Collections, Smithsonian Institution, Washington, D.C., transcribed by author.

as a legit language, and many Deaf people had a lot of pride with identity. Now a lot of Deaf people are coming out of the woodwork.”¹⁵ Now that more than forty years have passed since the 1981 Festival program and Deaf culture has reached several new intersections in history, the time seems right to continue strengthening the cultural heritage of Deafness and to foster even more mutual understanding between Festival participants and Festival visitors.

¹⁵ Unidentified panelist in undated audio recording, from Festival of American Folklife, ca. June 1981, Ralph Rinzler Folklife Archives and Collections, Smithsonian Institution, Washington, D.C., transcribed by author and Abigail Hobart.

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Gallaudet University has posted fifty-two videos from the 1981 Folklife Festival program at <http://videocatalog.gallaudet.edu/?search=Festival+of+American+Folklife>

The Smithsonian Transcription Center used volunteers to transcribe audio recordings from the 1981 Folklife Festival program, <https://si-siris.blogspot.com/2019/10/transcribing-deaf-folklore-from-1981.html>

Transcriptions of audio logs from the 1981 Folklife Festival program, <https://transcription.si.edu/project/18588>

Audio recordings and transcripts of conversations, <https://transcription.si.edu/project/18010> and others

Social Safety and Disability Erasure: The Sacrifice of the Disabled Body

Hunter Duncan¹

Danielle Clapham²

Over the last three years, COVID has created a broader cultural reflection on the bodymind and has called into question the stability of “ability.” As a whole, the COVID-moment has shifted how the public thinks about access and has also shifted the language of accommodation to make it more ubiquitous across communities. While this presents an opportunity to transform public understanding of disability towards a more socially recognized model, it simultaneously highlights the ways in which a non-disabled-oriented society has not, does not, and will not reform itself for the disabled body. Our paper questions the ways in which disability, ability, and access are made meaningful within our current cultural context of the COVID-19 pandemic, using disability in higher education as our central framework. The question we are raising in our presentation is simultaneously one of hope and of skepticism: how can we leverage the opportunities provided by increased attention to access during the pandemic while not diminishing the ongoing discrimination and challenges faced by disabled people in large part because of the pandemic? While we admit that our paper may raise more questions than it answers as we continue to live through and learn within the confines of the pandemic, our hope is that this essay will generate more complex conversations around disability to lead us toward greater change.

It is important to note that our discussion, definitional framework, and exploration of disability focuses on the United States. As a result, the terminology we use is largely based around disability language, identity, and legal definitions as they are defined by the Americans with Disabilities Act and the Disability Studies field in the United States. Additionally, we specifically explore the intersection of disability and COVID-19 within the context of higher education. We contend that higher education can serve as a case study on COVID accessibility issues that exist in society, and in many ways individuals in the context of higher education may experience some increased effects of COVID-19, including higher rates of anxiety and

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depression,³ particularly for people with disabilities.⁴ As Wang et al. indicate, young adults with disabilities were likely to experience more social isolation during the pandemic than older adults, likely because they are “at significantly higher risk for severe illness and death due to COVID-19 than their nondisabled peers.”⁵ With these findings in mind, we believe higher education is a vital area to study the intersection of COVID-19 policies and beliefs and disability, as universities often function as micro-environments wherein we can take a closer look at access, its impact on physical and online spaces, and the people who inhabit those environments. As both faculty and staff in higher education, we bring to light our unique experiences, shared responsibilities, and individual ideas about disability, access, and accommodations.

“Silver Linings”

As the public became subject to more access barriers due to the COVID-19 pandemic in 2020, many non-disabled people became aware of the need for accessibility measures that they may not have previously considered reasonable. Telecommuting, for example, became a norm in many industries for disabled and non-disabled workers alike, and some researchers wondered whether increase in telework may be a “silver lining” for workers with disabilities if the COVID-era “new normal” could be carried into a post-pandemic world.⁶ Even among Disability Studies scholars, there was an early tendency to try to find potential positives in the accessibility measures put in place during the spring of 2020; as Block, et al. note, “We are already seeing the emergence of new technologies and socialites that have come into being as a result of the Covid-19 pandemic....In the midst of physical isolation, we have been granted levels of intimacy and access that some of us have never experienced before.”⁷

³ Alyssa M. Lederer et al. “More than Inconvenienced: The Unique Needs of U.S. College Students During the COVID-19 Pandemic,” *Health and Education Behavior* 48, no. 1 (2020): 14-19.

⁴ Eleonora Iob, Andrew Steptoe, and Daisy Fancourt. “Abuse, Self-Harm and Suicidal Ideation in the UK During the COVID-19 Pandemic.” *British Journal of Psychiatry* 217, no. 4 (2020): 543-546, <https://doi.org/10.1192/bjp.2020.130>. They found that people with disabilities were twice as likely to report thoughts of self-harm and three times as likely to engage in self-harm behaviors.

⁵ Ken Wang et al. “Predicting Depression and Anxiety Among Adults With Disabilities During the COVID-19 Pandemic,” *Rehabilitation Psychology*, Advanced online publication (2022); 8.

⁶ Lisa A. Schur, Mason Ameri, and Douglas Kruse. “Telework After COVID: A ‘Silver Lining’ for Workers with Disabilities?” *Journal of Occupational Rehabilitation* 30, no. 4 (2020): 521-536, accessed February 25, 2022.

⁷ Pamela Block et al., “Introduction to the Special Issue: Disability and Covid-19,” *Disability Studies Quarterly* 41, no. 3 (2021).

The same was true on college campuses where the changing environment made disability and access visible for students, staff, and faculty who may have been previously unaware of its presence. Access no longer existed as a sole responsibility of the disability-services office. Instead, other offices on campus like residence life, libraries, and writing centers needed to address access within their own spaces, both in-person and virtually. For example, at Purdue, where Hunter works, the Disability Resource Center (DRC) is in conversations with the library systems to discuss training for staff members on ways to make the reference platform and student-librarian interactions more inclusive and accessible. Another example is the DRC's partnership with Orientation Programming, who recognized that offering multiple modes of "the student experience" could be made possible through in-person, virtual, and inclusive design practices.

Access changes also became necessary in classrooms, as the pandemic shifted the focus of access toward a more proactive rather than reactive model. Professors, TAs, and instructors began to automatically create accessible course content, like captioned media, flexible deadlines, extended time on exams, and lecture recordings. Prior to the pandemic, these accommodations were not usually included in course syllabi and were something that students had to often ask for to receive access in their classrooms. Understandably, many people with disabilities saw a potential shift in public understanding of disabled experience as an avenue to advocate for long-needed changes.

COVID Access Myth

However, despite the accessibility gains made possible in the pandemic, it is overly simplistic to frame COVID-era accessibility measures solely in a narrative of progress. There are certainly victories that can and should be celebrated, but those individual victories do not negate the systemic issues of ableism and inaccessibility that persist in (and in some cases are exacerbated by) the pandemic. In fact, in many cases, the existence of new accessibility tools has created a false sense of resources, information, and support. So, while COVID powerfully reshaped how we create access in a classroom, it simultaneously complicated and blurred the distinctions between access needs and personal preferences.

Essentially, the pandemic has created the appearance of universal access for all, even though new accessibility measures are primarily designed for non-disabled people affected by

COVID-19 and serve those with disabilities as an afterthought. As Flowers notes, “responses to a world made newly inaccessible by COVID-19 have taken the disorientation of the able-bodied subject as their starting point, seeking to ‘reorient’ the able-bodied subject through technologies that serve to maintain the ways in which the able-bodied subject can reach those objects placed out of reach.”⁸ By continuing to center on non-disabled experience, COVID-era accessibility measures remain surface level and perpetuate the marginalization of disabled bodies for whom many of these new resources remain either insufficient or unobtainable.

While the pandemic may have broadened our concepts of an accessible world, we need to ask, *for whom is the world made accessible* and, *who is credited for the access*? While accessibility measures were openly available for non-disabled people, accessibility is often a *conscious* and a *deliberate* effort for disabled people. For many, the effort that goes into investigating and planning around accessibility needs comprises the “invisible work” of being disabled in an inaccessible world.⁹ As Jan Grue notes in his article for the Guardian, “The only way to escape this work, short of a utopian remaking of the world, is to stop living. Disabled people know this. They know that they have the right to access, in principle and in law, but that they must work, continuously, in order to claim this right.”¹⁰ For non-disabled people, however, accessing the “new normal” was an accident, a collective coincidence because of the pandemic. Though many accessibility were beneficial for disabled individuals as well, it is essential to remember that the benefits to disabled people were merely side effects of the need to adjust to the normative bodymind.

Exacerbating this is the public perception of these measures as sufficient, in part because of the ways that the language of access and accommodation has entered the public vernacular. Once the purview of Disability Studies and disability services, the terms access and accommodation are now frequently used in public discourse surrounding COVID-19. As

⁸ Jonathan Flowers. “COVID-19 and the Disinheritance of an Ableist World,” *International Journal of Critical Diversity Studies* 4, no. 1 (2021): 115-116.

⁹ Arlene Kaplan Daniels, “Invisible Work.” *Social Problems* 34, no. 5 (1987): 403-415. Kaplan’s concept of “invisible work” critiques our social understanding of work as something that exists outside of the home and only valued as long as it relates to pay. The concept has also been applied to other forms of unpaid physical and emotional labor like that undertaken by disabled people to manage the emotions of non-disabled people and gain access to necessary resources.

¹⁰ Jan Grue, “The High Cost of Living in a Disabling World,” *The Guardian*, November 4, 2021, accessed February 25, 2022, <https://www.theguardian.com/society/2021/nov/04/the-high-cost-of-living-in-a-disabling-world>.

multiple communities borrow and revise these terms in the context of COVID there is a need to rhetorically analyze how these terms function in a disability context to distinguish between broader policies of inclusion and more person-specific modifications to the built environment. Accommodations, within the ADA, are a modification of policy.¹¹ Access, however, refers to “the power, opportunity, permission, or right to come near or into contact with someone or something.”¹² In a Disability Studies context, the goal of accessibility is to achieve equity through opportunity. Therefore, while accommodations can contribute to access, they are ultimately a reactive method to achieving it. The pandemic blurred the distinction between access and accommodation by applying them to an array of human experience. For example, during COVID, closed captions on Zoom presentations provided access to a multitude of users (disabled or not) whereas pre-COVID, closed captions were often viewed as a specific accommodation for those with a hearing impairment. For those of us who work in higher education, we’ve recently been inundated with questions of: *how do I implement this as an accommodation, or how can I create access (equitable experiences) for all?* Tensions arise when things that used to be considered specific accommodations requiring case-based policy modifications are now more broadly understood as core features of classroom accessibility. Student, staff, and faculty expectations around what access and accommodation mean and what they look like in the classroom and campus environment are now being challenged in ways that we’ve never seen before.

Additionally, the processes for gaining access and accommodations have become increasingly complicated as we adjust to new forms of “normalcy.” On the surface, new public perceptions of what is accessible should have simplified conversations around disability. However, as more people adopt the language of accommodation and access, the discussions we are having become increasingly more complicated. Who needs access? Who needs accommodations? Students now commonly use phrases like “My professor was very accommodating during COVID with online exams because they extended the time for

¹¹ Department of Labor. “Accommodations. Office of Disability Employment Policy. n.d. Accessed 25 February 2022, <https://www.dol.gov/agencies/odep/program-areas/employers/accommodations#:~:text=Under%20Title%20I%20of%20the,done%20during%20the%20hiring%20process>.

¹² Bess Williamson. “Access,” in *Keywords for Disability Studies*, edited by Rachel Adams, Benjamin, Reiss, and David Serlin, 14. New York: NYU Press, 2015, accessed February 25, 2022. <https://keywords.nyupress.org/disability-studies/essay/access/>.

everyone,” or, “My professor is now less accommodating in the in-person environment. How can I get accommodations?” Essentially, the pandemic raised the bar for what access and accommodations look like on a day-to-day basis and changed public expectations of both. This expectational shift thus changed the way people have come to understand disability. For example, those who may have previously resisted identifying as disabled are now seeking disability diagnoses because of the access that the pandemic gave them. In higher education specifically, disability, access, and accommodations are increasingly at the forefront of conversations among students, staff, and faculty because of this uptick in students seeking formal accommodations.¹³

Disability Marginalization and the “Return to the Normal”

Unfortunately, as the pandemic persists into its third year, the social, cultural, and environmental flexibility of access and accommodation on college campuses conflicts with the availability of public and campus resources. For example, telehealth and telework options that allowed many disabled people to access medical care and continue attending school during the pandemic are now being removed as public health emergency (PHE) initiatives expire.¹⁴ Public mask mandates and vaccine mandates that allowed many disabled people to safely leave their homes are being repealed¹⁵ and, in some cases, banned.¹⁶ Within higher education, almost 90% of campuses returned to in-person learning for the 2022 spring semester, even though many have not required students, faculty or staff to be vaccinated or to wear masks.¹⁷

¹³ Disability Resource Center, “Annual Report 2020-2021,” Purdue University, n.d., Accessed February 25, 2022, <https://www.purdue.edu/drc/about/report.php>. The DRC at Purdue saw a 16% increase in students requesting accommodations between AY 18-19 and AY 19-20. While there was not an increase between AY 19-20 and AY 20-21, the office anticipates higher numbers in their AY 21-22 report.

¹⁴ Stacy Weiner. “What Happens to Telemedicine after COVID-19?” Association of American Medical Colleges. Last modified October 21, 2021, <https://www.aamc.org/news-insights/what-happens-telemedicine-after-covid-19>.

¹⁵ “The U.S. States That Are Ending Mask Mandates,” The New York Times online, February 23, 2022, <https://www.nytimes.com/article/mask-mandates-us.html?auth=login-google>.

¹⁶ Stacey Decker. “Which States Ban Mask Mandates in Schools, and Which Require Masks?” Education Week, Last modified February 25, 2022, <https://www.edweek.org/policy-politics/which-states-ban-mask-mandates-in-schools-and-which-require-masks/2021/08>; Claire Raj. “How Bans on Mask Mandates Affect Students with Disabilities – 4 Questions Answered.” The Conversation. Last modified September 10, 2021, <https://theconversation.com/how-bans-on-mask-mandates-affect-students-with-disabilities-4-questions-answered-167024>.

¹⁷ Josh Moody. “Most Colleges Resume In-Person Classes,” Inside Higher Ed, January 6, 2022, <https://www.insidehighered.com/news/2022/01/06/colleges-resuming-person-classes-amid-omicron>.

While these “return to normal” initiatives are often celebrated by non-disabled people looking forward to the end of the pandemic, disability rights activists emphasize that these rollbacks in preventative measures and protections are re-marginalizing disabled people after the potential for access was made clear. As disability rights activist Alice Wong notes in an interview with NPR, “There is a casual acceptance that the pandemic will turn into something endemic, an inevitability that 'everyone' will get COVID eventually...Leaders, medical professionals and public health experts have said something along those lines with zero acknowledgement that people will still die and those deaths will be disproportionately from high-risk groups.”¹⁸ Jordan Grunawalt refers to these “return to normal” movements as necropolitics in which “some lives (poor, elderly, disabled) are seen as weighing the country down, so they must be sacrificed in order for the majority to return to normal.”¹⁹ Overall, the accessibility measures and increased public awareness around disability and accommodation linked to COVID-19 should not be oversimplified as wholly positive when in fact such awareness and temporary accommodations can lead to the further oppression of disabled people as public concern over COVID wanes.

A Note of Hope

Despite these challenges, however, we wish to end on a message of hope. As much as the pandemic has highlighted inaccessibility and existing inequities, it also provides us with a fruitful opportunity. By attending to the ways in which access, accommodation, disability, and the concept of normalcy are defined and shaped within the purview of the pandemic and in the idea of a post-pandemic future, we suggest ways that higher education can continue to adapt to this ever-changing environment. We advocate continued change in three areas: ideological, practical, and social.

Ideological

¹⁸ Lesley McClurg. “There's One Population that Gets Overlooked by an 'Everyone Will Get COVID' Mentality,” NPR online, January 26, 2022, https://www.npr.org/sections/health-shots/2022/01/26/1075549754/covid-disabled-immunocompromised?utm_source=facebook.com&utm_term=nprnews&utm_medium=social&utm_campaign=npr&fbclid=IwAR2uKnWakZF07k2jdlhAOBLNDDkx0vy-8UCbOFag5aabmborEbgUMtxKz8.

¹⁹ Jordan Grunawalt. “The Villain Unmasked: COVID-19 and the Necropolitics of the Anti-Mask Movement.” *Disability Studies Quarterly* 41, no. 3 (2021). Accessed February 25, 2022. <https://dsq-sds.org/article/view/8343>.

As our previous discussions of access and non-disabled subjects have shown, COVID has helped non-disabled people in higher education understand access and disability as shared experiences as built environments on campuses were adapted to meet the broader accessibility needs during the pandemic. Indeed, on many campuses, including ours, problems that would have previously been the sole responsibility of disability services, human resources departments, or offices of institutional equity are now tackled by a larger range of campus partners.²⁰ The success of COVID-era accessibility measures and projects reveals the capacity of institutions to fix inaccessibility issues. As Aydos, Navarini, and Oliveria note, “If before the pandemic, companies used the lack of suitable technology or people’s resistance to them as a reason to keep people with disabilities from the workplace, the pandemic evinced that these were no more than false excuses.”²¹ Pandemic-era measures illustrate that non-disabled faculty, staff, and administrators can and should prioritize accessibility needs as essential to university operations.

Practical

As many researchers have noted, COVID-19 illustrated the importance of student support services on college campuses, including disability services. As students’ need for mental health support, virtual learning options, and accommodations grew, campuses and state legislators rose to the challenge by providing new funding sources and programming. However, it is vital to remember that these needs will not magically disappear as COVID cases decline. As Lederer et al. implore, student services, including disability services, “should be prioritized as a critical investment in student success” even as the inevitable post-COVID budget cuts roll in.²² Additionally, institutions of higher education should continue advocating at the state and federal level for continued legislation supporting telehealth and technological access to student services and mental health counseling after COVID-era grants end and funding wanes.²³ Finally, offices of disability services should revisit and revise their procedures for accessing accommodations

²⁰ For a fascinating example of these new cross-departmental collaboration, see the IACM beta app designed by the EPICS at Purdue in conjunction with the DRC to help students, faculty, and staff identify map accessible entrances and tools on campus: <https://testflight.apple.com/join/eKqfGQ4I>.

²¹ Valéria Aydos, Daniela Navarini, and Bernardo Oliveria. “The Paradox of ‘Remote Working’ in Covid-19 Pandemic Times: Disability, Inclusion, and Accessibility in Brazil.” *Disability Studies Quarterly* 41, no. 3 (2021). Accessed February 25, 2022. <https://dsq-sds.org/article/view/8359/6188>.

²² Lederer et al., 17.

²³ Lederer et al., 17.

for students where relevant, as the increased need for accommodations is likely to persist and even grow as COVID-related disabilities continue to affect campus populations.²⁴

Social

The success of COVID accessibility measures on campuses was in large part the result of increased campus partnerships. As we look ahead to a post-pandemic future, campuses must make a commitment to maintaining relationships across departments that emerged as a matter of happenstance during the pandemic. Partnerships like those detailed above at Purdue between disability services and other campus departments cannot be forgotten in the “return to normal.” In practice, offices of disability services should continue their outreach to these new partners to offer resources and support for campus initiatives and proactively work to make new initiatives accessible from the start. Additionally, other campus departments should welcome new collaboration opportunities with disability service offices to continually improve campus accessibility. With proper attention and planning, these partnerships could result in campuses that are built to be disability forward rather than relying on retrofits to meet student needs.

In addition to fostering relationships across campus services, Disability Studies as a field can and should facilitate more communication between the academic and administrative sides of our work. The failure of the COVID-access myth is its continued centering of non-disabled voices, and it is essential to reposition the disabled bodymind experience back into the center of the conversation around access in higher ed as we emerge from the pandemic. The sad reality is that disabled voices are more likely to be found in the academic side of Disability Studies than in administrative offices. This makes it particularly essential to include academic Disability Studies scholars in administrative decision making and campus partnerships.

That said, it would be just as easy to dismiss the importance of administrative Disability Studies in supporting ongoing disability initiatives post-COVID. It is vital to remember that our field arose out of the disability rights movement which was itself concerned with practical matters of legislation, equity, and accommodation. In the years since the passage of the ADA, many of the battles of compliance and accommodation have been fought in disability service offices by administrative workers. Administrative disability advocates have valuable insights

²⁴ Accessible Campus Alliance. “Beyond ‘High-Risk’: Update for 2021.” Last modified August 25, 2021, <https://bit.ly/accesscampusalliance>.

and contributions to offer to academic conversation around disabled experience in part because of the contact they have with students and faculty in the accommodations process.

In many ways, the pandemic is a unique moment for academic and administrative collaboration because it created new situations and led to new avenues for exploring what access can look like in higher ed. Our collaboration on this paper is itself a model of this kind of relationship. We, in our partnership, bridge the gap between the academic side of higher ed and the administrative, and we believe these two sides of Disability Studies must also join forces to maximize the COVID moment for the sake of access.

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Collaborative Approach Between Programs: Improving Communication Access with Deaf People Through Nursing Simulation

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Introduction

For many years, the health care field has pursued the service goal of patient-centeredness.⁶ According to the Institute of Medicine, the desired goal of patient-centered health care is for practitioners to be “respectful of and responsive to individual patient preferences, needs, and values.”⁷ Many constructs and models have been used to quantify this concept, but at its core, patient-centeredness relies on effective communication.⁸ Dialogue is essential for health care settings, requiring the patient to receive important information from the medical professional, as well as the medical professional understanding and responding to important information conveyed by the patient.

Communication with health care providers can be challenging, even when the patient and health care provider share a language and culture. Research has shown that better health care outcomes are achieved when patients have a positive relationship and interaction with their health care provider.⁹ However, when patients identify with a culture and use a first language that is different from their health care provider, they may experience service and information

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⁷ Institute of Medicine. *Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century.* (Washington: National Academies Press, 2001).

⁸ Steven Barnett et al., “Deaf Sign Language Users, Health Inequities, and Public Health: Opportunity for Social Justice,” *Preventing Chronic Disease* 8, no. 2 (2011): A45.

⁹ Chase Wesley Raymond, “Conveying Information in the Interpreter-Mediated Medical Visit: The Case of Epistemic Brokering,” *Patient Education and Counseling* 97, no. 1 (2014): 38-46.

barriers when seeking medical treatment, resulting in less adherence to treatment plans or avoidance of seeking medical care.¹⁰

Faculty of two distinct programs at a large midwestern university created an opportunity to experience patient-centered service provision with deaf volunteers. Nursing faculty wanted their students to experience the dynamics of engaging patients who are deaf and use American Sign Language (ASL) as their primary language. Interpreting faculty sought an opportunity for students to experience authentic medical interactions. The two sets of faculty agreed to use the nursing program's simulation lab and deaf volunteers to model professional collaboration for service provision.

Deaf people whose primary language is ASL, which is distinct from English with its own complex grammar and distinct syntax, vocabulary, and discourse style,¹¹ require special communication access considerations. A medical appointment with a deaf patient without appropriate communication accommodations can result in miscommunication, misinformation, misdiagnosis, and mistrust.¹² Deaf people often experience inequities in health care which lead to poor health¹³ and lower health literacy¹⁴ than their non-deaf counterparts.¹⁵

One option for providing communication access to deaf patients is to work with interpreters to facilitate dialogue between the medical professional and the deaf patient, enabling both sides to give and receive information more easily. Although a seemingly obvious prescription for a communication impasse, this is not as simple as it sounds. Too often, medical appointments for deaf patients continue without the use of an interpreter, due in part to a lack of awareness by providers of the importance of communication accommodation or the lack of available interpreters.¹⁶ This combination of potential lower health literacy, lack of interpreters,

¹⁰ DeAnne K. Messias, Liz McDowell, and Robin Dawson Estrada, "Language Interpreting as Social Justice Work: Perspectives of Formal and Informal Healthcare Interpreters," *Advances in Nursing Science* 32, no. 2 (2009): 128-43.

¹¹ Valli, Clayton, Ceil Lucas, Kristin Mulrooney, and Miako Villanueva, *Linguistics of American Sign Language: An Introduction (5th ed.)* (Washington: Gallaudet University Press, 2011).

¹² Lisa Iezzoni et al., "Communicating about Health Care: Observations from Persons who are Deaf or Hard of Hearing," *Annals of Internal Medicine* 140, no. 5 (2004): 356-62.

¹³ Barnett et al., A45.

¹⁴ Health literacy meaning significant gaps in basic health knowledge.

¹⁵ Robert Q Pollard and Steven Barnett, "Health-Related Vocabulary Knowledge Among Deaf Adults," *Rehabilitation Psychology* 54, no. 2 (2009): 182-5.

¹⁶ David A. Ebert and Paul S. Heckerling, "Communication with Deaf Patients. Knowledge, Beliefs, and Practices of Physicians," *The Journal of the American Medical Association*, 273, no. 3 (January 1995): 227-9; Laurie A.

and health care providers who are unaware or unprepared to meet this population's specific needs highlights the frustration of countless deaf people. A deaf community spokesperson shared insights on behalf of the Deaf Community, affirming, "We deaf people just want to be able to go to our appointment worried about our health just like everyone else."¹⁷

The exchange of medical information, even at routine office visits, can become perilous when the patient cannot fully participate in discussions regarding safe uses of medications, or complex, even risky, decision-making expectations.¹⁸ Expecting deaf patients to rely upon written texts creates a type of double jeopardy in which the patient with inadequate health-related knowledge is expected to comprehend critical information presented in their second language, English.¹⁹ Thus, patient health care information should be communicated in sign language to achieve patient-centered care and positive health outcomes.

A further complication is the lack of specialized training for interpreters in health care settings.²⁰ Medical interpreting necessitates accuracy due to its high risk/high stakes nature.²¹ Accuracy in the health care setting is interpreters' most important objective. They must have a strong background in medical terminology, knowledge, and understanding of medical procedures and treatments.²² However, no standardized or recognized strategy exists for preparing interpreters with this medical information.²³

Simulation

Previously, nursing students developed professional skills primarily in actual medical

Swabey and Karen Malcolm, *In Our Hands: Educating Healthcare Interpreters* (Washington: Gallaudet University Press, 2012).

¹⁷ Dawn Croasman (deaf consumer), in email to the author, May 23, 2019.

¹⁸ Teri Hedding and Gary Kaufman, "Health Literacy and Deafness: Implications for Interpreter Education," in Laurie A. Swabey & Karen Malcolm (Eds.), *In Our Hands: Educating Healthcare Interpreters* (164-89). Washington: Gallaudet University Press, 2012. muse.jhu.edu/book/16305; Lisa Iezzoni et al., 356-62.

¹⁹ Ewa Domagała-Zyśk, "Vocabulary Teaching Strategies in EFL Classes for Deaf and Hard-of-Hearing Students," in *English as a Foreign Language for Deaf and Hard-of-Hearing Persons: Challenges and Strategies*, ed. Ewa Domagała-Zyśk and Edit H. Kontra (Newcastle upon Tyne, U.K.: Cambridge Scholars Publishing, 2016), 135-52.

²⁰ Laurie A. Swabey and Quincy Craft Faber, "Domains and Competencies for Healthcare Interpreting," in *In Our Hands: Educating Healthcare Interpreters*, ed. Laurie Swabey and Karen Malcolm. (Washington: Gallaudet University Press, 2012), 1-26.

²¹ George Major et al., "What Happens Truly, Not Textbook?" Using Authentic Interactions in Discourse Training for Healthcare Interpreters," in *In Our Hands: Educating Healthcare Interpreters (The Interpreter Education Series 5)*, ed. Laurie A. Swabey and Karen Malcolm (Washington: Gallaudet University Press, 2012), 27-53.

²² Hedding and Kaufman, 164-89; Major et al., 27-53.

²³ Swabey and Faber, 1-26.

settings, but today's nursing programs face diminished access to clinical situations. McCarthy and Wyatt²⁴ listed top barriers to traditional pediatric clinical experiences as competition for and general lack of clinical sites, limited preceptors, lack of hands-on opportunities, limited experiences with medication or safety concerns, and now COVID.²⁵ Furthermore, a National League of Nursing (NLN) survey found hospital policy barriers and growing student restrictions imposed by hospitals limit students' ability to fully practice the role of the registered nurse in actual health care settings.²⁶ Similar barriers exist for programs that prepare sign language interpreters. Interpreting faculty struggle to provide authentic experiences working with health care providers and rendering medical information from spoken English to ASL and vice versa.

Simulation in health care education is designed to replicate real clinical situations in a safe environment. The International Nursing Association for Clinical Simulation and Learning (INACSL) states that the specific purpose of simulation is to "promote, improve, or validate a participant's performance."²⁷ O'Donnell et al. found that students provided with realistic simulated clinical situations experienced improved critical thinking and communication skills.²⁸ Validating the importance of simulation, some nursing boards, such as Ohio's, have approved up to 100% replacement of traditional clinical hours with simulation in specialty areas such as pediatric and obstetrical nursing.²⁹

In the Framework for Action on Interprofessional Education and Collaborative Practice, the World Health Organization proposed embedding interprofessional training in health care disciplines.³⁰ With increasing numbers of non-native English speakers accessing the health care system, nurses and interpreters frequently find themselves working together in dynamic, unpredictable environments, requiring both professionals to

²⁴ Ann Marie McCarthy and Janet S. Wyatt, "Undergraduate Pediatric Nursing Education: Issues, Challenges and Recommendations," *Journal of Professional Nursing* 30, no. 2 (2014): 130–38.

²⁵ Garrett K. Chan, Janna R. Bitton, Richard L. Allgeyer, Deborah Elliott, Laura R. Hudson, and Patricia Moulton Burwell, "The Impact of COVID-19 on the Nursing Workforce: A National Overview," *Online Journal of Issues in Nursing* 26, no. 2 (2021).

²⁶ Pamela M. Ironside and Angela M. McNelis, "Clinical Education in Prelicensure Nursing Programs: Findings from a National Survey," *Nursing Education Perspectives* 31, no. 4 (2010): 264–5.

²⁷ INACSL Standards Committee (2016, December). "INACSL Standards of Best Practice: SimulationSM Participant evaluation," *Clinical Simulation in Nursing* 12, no. S (December 2016): S26–9.

²⁸ John M. O'Donnell et al., "NLN/Jeffries Simulation Framework State of the Science Project: Simulation Learning Outcomes," *Clinical Simulation in Nursing* 10, no. 7 (2014): 373–82.

²⁹ *Ohio Administrative Code*, 4723: Nursing Education Programs. Ohio Board of Nursing, Chapter 4723-5, 2017.

³⁰ World Health Organization. *Framework for Action on Interprofessional Education and Collaborative Practice*. Geneva, Switzerland: World Health Organization, 2010.
https://apps.who.int/iris/bitstream/handle/10665/70185/WHO_HRH_HPN_10.3_eng.pdf?sequence=1

be analytical and adaptive to unique demands while making extemporaneous, accurate, and ethical decisions.³¹ Raymond encourages nurses and interpreters to re-envision the interpreter's role and move from a siloed approach to a collaborative relationship.³² There are professional, logistical, and ethical advantages cited for providing opportunities for health care providers and interpreters to engage in shared educational experiences.³³ Thus, simulation can be a bridge between classroom and clinical environments and as a venue in which to address communication access concerns for deaf patients.

Methods

At the university where this study took place, nursing students take the pediatric-focused course, Health Care of Children, and interpreting students take Medical Interpreting and Community Setting Interpreting classes. In the fall of 2018, the authors secured Institutional Review Board approval for this study designed to answer the following research question: “How did nursing and interpreting students perceive the effectiveness of the simulation?”

Since nursing students outnumbered interpreting students, researchers employed random sampling for a subset of nursing students while all interpreting students completing either interpreting course were included. All potential participants were emailed the consent letter and a link to a 17-item questionnaire (two Likert-based items and open response follow-ups to those items) developed by the authors (see Appendix). The authors explained that participation in the survey was voluntary and if students chose not to sign the consent form, their survey terminated.

The Scenario

For the simulation, interpreting students worked with nursing students who were in a pediatric patient discharge scenario. Local deaf individuals volunteered as deaf parents during the simulation. This collaborative simulation allowed nursing students to provide discharge instructions to a deaf parent and interpreting students to hone their interpreting skills in a health

³¹ Karen Bontempo and Karen Malcolm, “An Ounce of Prevention is Worth a Pound of Cure: Educating Interpreters About the Risk of Vicarious Trauma in Health Care Settings,” in *In Our Hands: Educating Healthcare Interpreters*, ed. Laurie A. Swabey and Karen Malcolm (Washington: Gallaudet University Press, 2012), 105-30; Robyn K. Dean and Robert Q Pollard, *Demand Control Schema* (North Charleston, SC: CreateSpace, 2013).

³² Raymond, 38-46.

³³ Ineke H. M. Crezee, *Introduction to Healthcare*; Swabey and Faber, “Domains and Competencies,” (1-26).

care environment. This simulation met nursing objectives focused on communication and teaching and provided challenging opportunities for interpreting students to manage rapid turn-taking.

Nursing students were assigned to different roles (two assessment nurses, two nurses to complete discharge teaching to the deaf parent), and remaining students watched for behavioral outcomes listed on a handout. Two interpreting students were present at the bedside. One student interpreted the simulation and received interpreting suggestions and corrections, if warranted, from the other interpreter. Additional interpreting students observed through a double-sided glass partition and evaluated their peers from an adjoining room.

Active participants were told to treat the simulation as if they were in an actual hospital setting, given a brief description of the scenario, and given the patient electronic health record, including simulated order sheets, teaching materials, and documentation regarding any medications or care provided to the patient. Numerous safety issues were presented within the scenario.

The scenario lasted 20 minutes. During the first 10 minutes, nursing students performed a comprehensive physical exam. After approximately 10 minutes, students were encouraged to begin discharge teaching with interpreting students to facilitate communication with the deaf parent. After that, the 20-minute debriefing session began. Interpreting students reversed roles at this point. The debriefing was facilitated by an experienced nurse who gave each group of students a series of questions to discuss. This person also clarified information that may have been missed by students during the scenario.

Quantitative Analysis and Results

In order to compare the perceived effectiveness of the simulation, a Mann-Whitney test statistic was calculated. The Mann-Whitney test is a nonparametric alternative to an independent samples t-test. Given the smaller sample in the current study ($n = 26$), and that both items examined had ordinal data (Likert-scale response), use of this test statistic is appropriate.³⁴ Two questions were posed to participants that evaluated their self-perception of the effectiveness of

³⁴ Sidney Siegel and N. John Castellan. *Nonparametric Statistics for the Behavioral Sciences* (2nd Ed). (New York: Mc-Graw Hill, 1988).

the simulation. The first, “I am better able to communicate healthcare information to a deaf parent” was rated on a Likert-scale (1 = completely disagree; 2 = mostly disagree; 3 = slightly disagree; 4 = slightly agree; 5 = mostly agree; 6 = completely agree). Results indicated a statistically significant difference between groups of students ($U = 173.00$, $p = .020$), indicating that nursing students (Median = 6) were more likely to agree with the question than interpreting students (Median = 5). The second question, “Will this simulation affect the way you communicate with a deaf person or their family member?” was also rated on a Likert-scale (1 = definitely not; 2 = probably not; 3 = possibly; 4 = probably; 5 = very probably; 6 = definitely). However, the difference between Nursing (Median = 5) and interpreting students (Median = 5) was not statistically significant ($U = 83.50$, $p = .195$).

Notably, responses to both prompts appeared to have a heavy skew towards higher agreement. To test for this, a Kolmogorov-Smirnov one-sample goodness-of-fit test was used to evaluate the distribution of responses for each item. The Kolmogorov-Smirnov test is preferred to the Chi-Square test when examining smaller samples, as well as ordinal data (Siegel & Castellan, 1988). Results were statistically significant for both the first ($D = .270$, $p < .001$) and second ($D = .258$, $p < .001$) prompt, indicating that a randomly selected response from this sample is significantly more likely to be positive than negative on either prompt. In considering both sets of non-parametric tests, results suggest a heavy skew towards agreement with the first prompt and perceiving a high probability the simulation will affect future practice in the second. However, nursing students were more likely to provide the highest rating regarding ability to communicate healthcare information to deaf parents than interpreting students.

Qualitative Analysis and Findings

Open-ended question asked if students found the simulation beneficial in addressing communication needs with the deaf parent. Gratefulness emerged from interpreting students' responses, indicating that simulation was a place where they could hone their medical knowledge and interpreting prowess. Interpreting students consistently stated that the simulation provided them medical interpreting practice within an authentic medical environment, helped them with medical vocabulary, and allowed them to interact with the nursing students.

A nursing student expressed that they had a greater sense of empathy for deaf individuals going through “systems that are fundamentally not designed for them.” Nursing relies upon verbal communication for almost every encounter, a distinct disadvantage for someone who cannot/prefers not to communicate verbally. Nursing students consistently mentioned how they appreciated the opportunity to practice medical communication with interpreters, and realized they needed to be patient to accommodate the extra time needed for the interpreting process. One student noted,

We learn in nursing school how to communicate through interpreters but have little to no opportunity to actually practice this skill in the clinical setting. This experience brought the simulation to life and made it a very real testament to the importance of interpreting services in health care.

Many described the experience as positive and beneficial but also intimidating. One student remarked that “... it was hard at times to tell if the message I was sending verbally was being received by the parent.” Nursing students observed that in the future, they would speak directly to the patient when communicating through an interpreter, as opposed to speaking in third person.

Many interpreting students expressed that, unlike nursing students, they were already comfortable communicating with deaf individuals; however, they commented that they learned new signs or ways to show medical concepts to improve their communication. Both groups of students identified the importance of positioning and eye contact. One interpreting student mentioned that the deaf person “require[d] consistent eye contact and a direct line of sight from her nursing staff” and noted that this did not always occur.

When respondents were asked if they were better able to communicate health care information, both interpreting and nursing students had unique responses. Interpreting students consistently mentioned the importance of understanding medical jargon. This authentic exposure increased their awareness of the need to become familiar with it. Nursing students consistently mentioned appreciation for the new experience of working with an interpreter and deaf person.

Students were asked about what surprised them most about the simulation experience. Interpreting students noticed that the nursing students were tentative in the simulation. They were surprised that nursing students had not encountered a deaf person and were inexperienced with communicating through an interpreter. Interpreting students were impressed with how real the situation felt and how willing nursing faculty and students were to interact with the deaf person. Nursing students were most surprised by the deaf volunteer's patience during the interpretation process.

Discussion

In the cross-disciplinary collaboration described in this paper, interpreting students worked with nursing students in a realistic medical environment, and nursing students gained exposure to deaf people and the interpreting process needed to interact with the deaf community. Nursing and interpreting program faculty encouraged a team approach in which all members of the health care team could focus primarily on the deaf patient, so that they felt engaged and respected. This simulation experience allowed nursing and interpreting students to understand and appreciate the role of the other and to enact strategies to improve communication. Both groups of participants found the simulated experience to be beneficial and felt it gave them a safe environment in which to practice.

Nursing students stated that their biggest challenges were positioning, the need to wait for interpreted messages to be relayed; the importance of speaking, and the importance of waiting for the deaf participant to read or look at written texts first. Interpreting students felt their greatest challenges were conveying medical terminologies and adapting to the interactive pacing.

Limitations

A limitation in the current study was that this was only one type of simulation experience with only one population. There was limited medical terminology used, and no medical equipment or procedures to explain. There was a fairly small number of participants. Additionally, in the scenario, the deaf volunteers had medical schema, high language skills, and were comfortable with the interactive nature and expectations of a health care dialogue. However, students did

not have the opportunity to work with a more diverse set of deaf volunteers who may not have possessed all these capabilities.

Areas for Future Research

Students should participate in nursing/medical interpreting simulations more often, and simulations should vary in terms of content, room layout, pace, and language level. Further research would verify whether students apply skills from their previous experiences. Students could be followed longitudinally, with pre- and post-tests. Also, a second simulation would mitigate some of the discomfort of the first simulation and allow students to work toward patient-centered health care.

Curriculum development and best practices pedagogy in the training of interpreters for medical interpreting need to be expanded. Additionally, more research on effective nursing/interpreting collaborations is needed to drive best practices. This type of interdisciplinary simulation would invariably extend to individuals who are not only deaf but other populations who have a first language other than English.

Conclusion

Faculty initiating this partnership recognized many potential benefits to both programs in preparing their students to provide services to deaf people in a specialized setting. In terms of faculty aspirations for the study, initial goals were successfully met as evidenced by faculty and student observation and comments from the deaf volunteers. Nursing students were able to work with individuals who processed language in a different way than they were accustomed. Interpreting students were able to relate medical information to deaf people in a realistic, dynamic, and unrehearsed setting. Future simulations should increase in risk and repercussions and deal with settings other than pediatrics. Collaborative endeavors in simulation have positive outcomes on experiential learning.

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Appendix

17-Item Questionnaire

- 1) Did you participate in an interpreted simulation between August 2017-present?
- 2) What is/was your major: American Sign Language/English Interpreting or Nursing?
- 3) How beneficial did you find this simulation to be in addressing the communication needs of the deaf parent?
- 4) As a result of this simulation, to what extent do you agree or disagree with the following statement? “I was able to identify the deaf parent's *communication needs*.”

Completely Agree, Mostly Agree, Slightly Agree, Slightly Disagree, Mostly Disagree, Completely Disagree

- 5) Describe some of those communication needs.
- 6) As a result of this simulation, to what extent would you agree with the following statement? “I am better able to communicate *healthcare information* to a deaf parent.” Completely Agree, Mostly Agree, Slightly Agree, Slightly Disagree, Mostly Disagree, Completely Disagree

7) Why or why not?

8) Describe two or three benefits you found from working with the deaf parent in this simulated experience?

9) Describe what the experience was like of communicating with a deaf person through a medical interpreting student?

10) Will this simulation affect the way you communicate with an interpreter (if you are a nursing student) or with healthcare professionals (if you are an interpreting student)?

Definitely, Very Probably, Probably, Possibly, Probably Not, Definitely Not

11) How?

12) Will this simulation affect the way you communicate with a deaf person or a family member?

13) How?

14) As a result of this simulation, to what extent would you agree or disagree with the following statement? "I was able to gain insight into the other's students' work goals and procedures."

Completely Agree, Mostly Agree, Slightly Agree, Slightly Disagree, Mostly Disagree, Completely Disagree

15) As a result of this simulation, to what extent would you agree with the following statement: "The deaf parent's response or lack of response impacted my professional decision-making."

Completely Agree, Mostly Agree, Slightly Agree, Slightly Disagree, Mostly Disagree, Completely Disagree

16) What surprised you the most about these interpreted simulations?

17) What did you learn from this experience that would benefit you the most in your career?

Prescription Paralympics: Medical Influence Across Elite Disability Sport History

Evan Baughman¹

Introduction

The Paralympic Games are the high-performance disability sport counterpart to the Olympic Games. Designed to parallel the Olympics, the Paralympics take place in the same host city as the Olympics several weeks after Olympic events conclude. This makes the Paralympics the second largest sporting event in the world by number of athletes, behind the Olympics.²

Interviews from this study evidence the existence of a managerial "caretaker mentality" that influenced Paralympic administrators throughout the history of the Paralympic institution. In line with the medical model of disability,³ the Paralympic "caretaker mentality" defines Paralympians primarily as patients, i.e. recipients of a service, rather than elite athletes. Additionally, the caretaker mentality repeatedly constrained the development of high-performance disability sport.

Methodology

This study was designed inductively to empower disabled athletes' perspectives within the study of disability sport, counter (dis)ableist bias, and allow for novel theoretical paradigms to emerge. Much of existing literature on the Paralympic institution relies heavily on able-bodied medical accounts of Paralympic history. In turn, scholars often overlook disabled athletes as valuable primary data sources. Because Paralympians—the primary actors behind the Paralympic movement—were not adequately considered within Paralympic research, I hypothesized that the dominant narrative of Paralympic history contained critical narrative gaps.

To address this empirical gap, I conducted semi-structured, one-on-one interviews with 22 retired Paralympians, two older active Paralympians, and a prominent, retired disabled Paralympic coach. One interview was conducted in-person, one interview was adapted to

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² Ian Brittain, *From Stoke Mandeville to Sochi: A History of the Summer and Winter Paralympic Games* (Champaign, IL: Common Ground Pub., 2014).

³ Michael Oliver, *The Politics of Disablement* (London: Macmillan, 1990).

written form for accessibility purposes, and the remaining interviews were conducted via Zoom video calls. This study's interview protocol did not include questions that asked about Paralympians' diagnoses or impairments. Questions were grouped into five themes: 1.) athletic career history, 2.) historical changes within their sport, 3.) medicine in disability sport, 4.) the Paralympian community, and 5.) the meaning of disability sport.

With the exception of a single disabled Paralympic coach, all participants are Paralympians. Participants were able to consent to an interview and participate in English. I acquired participant contacts first through the United States Olympic & Paralympic Committee (Team USA), who graciously emailed their alumni list on my behalf, and later via snowballing. The median participant age is 55 years old. The sample includes 23 Americans, 1 Canadian, and 1 Australian. 16 interviewees are men, and 9 are women. The most represented sport was wheelchair racing (10), followed by cycling (5), wheelchair basketball (3), goalball (2), swimming (2), sled hockey (1), skiing (1) and wheelchair athletics (1). Altogether, participants earned 35 gold, 30 silver, and 19 bronze Paralympic medals. A range of impairment types are represented in the sample, including paraplegic, quadriplegic, amputee, and blind athletes. No deaf athletes were represented in the sample, as deaf athletes have long organized a separate "Deaflympics." All participants are referred to with pseudonyms.

Background

The International Paralympic Committee (IPC), the Paralympics' nonprofit governing body, traces its legacy back to the United Kingdom's Stoke Mandeville Games (SMG). Alexandra, a retired wheelchair racer now in her mid-50's noted that the Paralympics "started during World War II. Dr. Guttmann—he's given credit with, you know, founding the Paralympic movement." Similarly, Bill, a retired wheelchair basketball player now in his late 60's claimed that "the entrée" for the Paralympic Games "was Stoke Mandeville, which was started by a neurosurgeon who really had a much more patronizing kind of model of sport."

The SMG began in 1948 at Stoke Mandeville Hospital, a British rehabilitation hospital that treated soldiers with spinal cord injuries during World War II. The hospital's director, neurologist Dr. Ludwig Guttmann, organized the SMG as a form of "total rehabilitation" for spinal cord injury (SCI) patients. Before Guttmann revolutionized medical care for SCI patients with intensely regimented rehab practices, spinal cord injuries were widely acknowledged as a

painful death sentence. In addition to medical treatment, Guttmann hoped that disability sport would transform previously hopeless SCI patients into productive, tax-paying citizens by cultivating “mental activity, self-confidence, self-discipline, a competitive spirit and comradeship.”⁴ The SMG organization was restructured and renamed several times before the IPC was founded after Guttmann’s death.⁵

As the SMG grew into the Paralympic Games, disabled athletes innovated their sports to compete more competitively and athletically. In doing so, disabled athletes transformed disability sport from medical therapy into elite, high-performance sport.⁶ Mike, a wheelchair racing Paralympian now in his mid-60’s, describes the 1980’s as a revolutionary era in disability sport:

The critical change came in 1980. The Games went from being a medical model to an athletic model slowly in the 80’s... Look at it this way, wheelchair sports in the 80’s was the equivalent to America in the 60’s. It was a *revolution* going on! And all of a sudden, in 1988, the Paralympics are at the Olympic Games. We were in the same arena that the AB's (able bodies) were two weeks before. (Mike)

During this time, the Paralympics began to mimic and share venues with the Olympic Games.^{7,8} However, scholars have not sufficiently addressed to what extent the SMG’s medicalized understandings of disability remained operative within the Games after competitions were relocated from Guttmann’s hospital lawns to major athletic venues.

Data

The “Caretaker Mentality”

Interviews with Paralympians reveal that Paralympic leadership organized and administered elite disability sport in accordance with a “caretaker mentality.” I borrow the term “caretaker mentality” from a participant who I call Matt, a retired Paralympian who has also published on

⁴ Susan Goodman, *Spirit of Stoke Mandeville: The Story of Sir Ludwig Guttmann* (London: Collins, 1986).

⁵ Brittain.

⁶ David Howe, *The Cultural Politics of the Paralympic Games* (London: Routledge, 2008).

⁷ David Legg and Robert Steadward, “The Paralympic Games and 60 Years of Change (1948–2008): Unification and Restructuring from a Disability and Medical Model to Sport-Based Competition,” *Sport in Society* 14, no. 9 (2011): 1099–1115.

⁸ Ted Fay and Eli Wolff, “Disability in Sport in the Twenty-First Century: Creating A New Sport Opportunity Spectrum,” *Boston University International Law Journal* 27, no. 231 (January 2009): 231–48.

the history of disability sport. The caretaker mentality is an ideology whereby Stoke Mandeville and Paralympic officials, often medical professionals, understood organizing disability sport as providing care for disabled athletes.

We started to recognize, particularly coming out of World War II, that there were people with disabilities who still had something to contribute, but we still we looked at those vets that got injured coming out of World War II as individuals who we needed to take care of... For the most part, around the world, you had this (caretaker mentality) because it was people from the medical profession looking after people with disabilities. And, so, they brought that caretaker mentality right into their interaction (with athletes) ... (Matt)

In this paper, I use Matt's notion of the caretaker mentality as a tool to analyze participants' stories throughout the history of the Paralympic institution. I argue that the caretaker mentality disempowered disabled athletes by casting them as recipients of a service, like medical care, rather than high-performance athletes. Second, I argue that the caretaker mentality is antithetical to the notion of high-performance disability sport and repeatedly constrained the development of elite disability sport by unnecessarily restricting disabled athletes' attempts to advance their athleticism.

Recipients of Service

The caretaker mentality was brought into the world of elite disability sport by medical professionals. In the early days of the Paralympic Games, particularly during the SMG era, those who managed the Games were almost entirely medical professionals. Four participants noted that elite disability sport during their career was led by medical professionals:

If you looked at some of these country organizations of wheelchair sports that went to Stoke (Mandeville)... they were highly populated by doctors... I don't think there was a team or regional organization that didn't have people from the medical field. (Nathan)

Many, however, are well aware that (the medical) community exercises too much influence in the governance of the sport... they continue to exert out of proportion influence. (Tony)

And in '78 at Stoke Mandeville, the executive committee was made up of virtually all doctors, and some local influential people. Well, Guttman traveled the world and picked up all the doctors put them on it. (Ethan)

The events were all run by a lot of physical therapists... And they just kind of bossed us around.
(Chris)

With doctors and physical therapists serving in most positions of power within the Paralympic institution, including top directorships and executive committee memberships, little room remained for disabled athletes to exercise agency over how their sport was competed and organized. Bill explained that disabled athletes were disempowered within their sports because medical leadership perceived Paralympians as recipients of their services.

Stoke Mandeville was really a top-down operation. The athletes were the recipients of a service. Everything about the sport was really driven by Guttman and the committees of—usually medical—personnel. Teams and athletes really weren't empowered to own the organization.
(Bill)

The caretaker mentality not only severely restricted disabled athletes' ability to self-determine within their sport. It stifled the development of disability sport as high-performance sport. According to Guttman and those like him, medical administrators knew what was best for disability sport, not the disabled athletes who invented, innovated, and compete in them. The Paralympics were understood as yet another form of medical modality to treat and benefit disabled people, not high-performance sport like its able-bodied Olympic counterpart.

Constrained Disability Sport Development

Disabled athletes repeatedly confronted anti-athletic restrictions on their sport created by Paralympic officials who were motivated by the caretaker mentality. For instance, quadriplegic athletes were restricted less strenuous competitions due to medically motivated concerns regarding their physical capabilities. Nathan, a quadriplegic wheelchair racer now in his early 60's, noted how his sport was restricted on the basis of medical concern.

I was at Stoke (Mandeville)... At that time in history, we're just at the beginning stages of expanding track events for quadriplegics. Up until '80, quadriplegics 'can't' and 'shouldn't' push their wheelchairs further than 100 yards. In fact, at Stoke, I think the track events were the 100-, the 40- and the 60-yard dashes. That was the sort of the international medical perception of the athletic or physiological performance capacity of people with spinal cord quadriplegia. (Nathan)

In fact, Nathan recounted how he was stopped by a team of Japanese doctors while warming up one morning at the Stoke Mandeville track. The doctors blocked his path and asked

where his team's medical doctors were. Concerned for his ability to adequately respire, they warned Nathan that quadriplegics should not exercise in the heat, though Nathan already trained by pushing 6 or more miles per day in his chair.

The caretaker mentality also led to rigid regulations on chairs for wheelchair racing:

The chair had to have push handles. In the 60's, the US team that went to Stoke Mandeville... lowered the backs of their chairs because, when they were pushing with those high backs, their arms would hit them. Well, then they were deemed illegal by the technical committee at Stoke Mandeville, and some athletes were just banned... the sport was very rigid. (Bill)

Leaders assumed that the standard rehab wheelchair were the fairest wheelchair for athletes with varying impairments to compete in. However, the standard rehab wheelchair also limited the speed that racers could propel themselves at. It would not be until much later, and after much protest, that the T-frame racing wheelchair would become legalized in Paralympic racing.

Under the caretaker mentality, Paralympic officials treated elite disabled athletes much like they were patients. Mike, a former wheelchair racer now in his mid-60's, claimed that Paralympic officials during his career "were always thinking about what was best for the medical treatment and care of the athlete." By doing so, many who governed the early Paralympic institution were unable to see that competitors like Mike were "committed athletes."

Discussion

The history of the caretaker mentality within the Paralympic Games further substantiates Oliver's medical model of disability⁹ and offers itself as a prominent and influential case for analysis. The early Paralympic Games were governed by mostly able-bodied, often medically trained, officials. Guided by the caretaker mentality, these well-intentioned officials frequently organized and regulated international disability sports events in pro-rehabilitation, yet anti-athletic manners. These medical ontologies disability underpin the history of Paralympic management.

Participants agreed that small gains had been made in gaining greater disabled athlete agency in their sport and representation within the IPC. Yet, Paralympians maintained that there

⁹ Oliver.

is still much more work to be done in order to be recognized as athletes who are equally legitimate as their able-bodied Olympian counterparts.

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Enhancing Speech Communication in the Built Environment for Those with Hearing Loss

Karen Keddy¹

Introduction

A vast majority of the population will at one time experience some form of hearing loss, either temporary or permanent (Maisel, Steinfeld, Basnak, Smith, and Tauke 2018). “About 1 in 5 people have some amount of hearing loss” (Stiles 2017, 101). Approximately 15% of American adults (37.5 million) aged 18 and over report some trouble hearing (CDC Summary Health Statistics for U.S. Adults 2014). “Universal design is a process that enables and empowers a diverse population by improving human performance, health and wellness, and social participation” (Steinfeld and Maisel 2012, 29). This updated and improved definition of universal design places emphasis on social participation. Hearing loss can have a dramatic impact on one’s quality of life creating a barrier to communication and hence, social participation.

Maisel, Steinfeld, Basnak, Smith and Tauke (2018) state, “The acoustic environment is one of the most neglected areas of design” (82). Mobility, vision, and cognitive disabilities have received much more attention than hearing disabilities. Accommodation for those with hearing loss is often marginalized in the design discourse. Exclusion of people with disabilities is well documented, but the exclusion and marginalization of certain groups within the disabled community needs more acknowledgement. Furthermore, marginalization of one type of disability within a disability needs to be acknowledged and addressed.

Throughout this paper, I will use the terms Deaf, Deaf culture and hard-of-hearing. Deaf with a capital ‘D’ is used to describe an individual or group of individuals for whom being deaf is central to their cultural identity (Bauman and Keane 2010, 20). In the Deaf culture, people inhabit a rich sensory world where vision and touch are a primary means of spatial awareness and orientation. Many use sign language, which is a visual-kinetic mode of communication and they maintain a strong cultural identity that is built around these sensibilities and shared life experiences (Bauman and Keane 2010). Being hard-of-hearing describes a condition of having

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some degree of hearing but it is definitely reduced or deficient hearing ability. However, it is important to note the distinct difference between the experiences of being Deaf and being hard-of-hearing. People who are Deaf identify with the Deaf community and use American Sign Language (ASL) as their primary means of communication, rather than speech.

People who are hard-of-hearing identify with the hearing community, they may wear hearing aids, speech read, and use their voices to speak. For the most part, the Deaf culture and those who are hard-of-hearing have completely different needs in terms of communicating. Therefore, the design interventions needed to support their needs will be different as well.

DeafSpace

A recent approach to designing for those who are Deaf and hard-of-hearing is based in DeafSpace philosophy. “Our built environment, largely constructed by and for hearing individuals, presents a variety of surprising challenges to which deaf people have responded with a particular way of altering their surroundings to fit their unique ways-of-being. This approach is often referred to as DeafSpace” (Gallaudet University Campus Design and Planning 2021). DeafSpace is informed by the ways in which deaf people interpret and inhabit space. DeafSpace seeks to place the user in the center of the design process and draws upon the experiential knowledge of Deaf users (Edwards and Harold 2014). There are five DeafSpace design principles: space and proximity, sensory reach, mobility and proximity, light and color, and acoustics. “The DeafSpace Design Guidelines are intended to guide and inspire the design of environments for deaf people that are completely responsive to, and expressive of, their unique ways of being. Many in the deaf community maintain strong social connections through, and identify with “Deaf culture” built around a shared language, life experiences and cognitive sensibilities” (Bauman and Keane 2010, 10).

Space and Proximity

A visual-spatial language such as ASL requires that people signing maintain enough distance to accommodate each other's' signing space when conversing. This space is typically greater than that maintained by people having a spoken conversation, and as more signers join the conversation, the space between them grows so that all participants can access the communication (Weebly 2015).

Sensory Reach

This refers to the needs of Deaf people to be spatially oriented and visually aware of the activities in their surroundings. Deaf people are highly attuned to visual and tactile cues such as shadows, vibrations, and the position of people in an environment. Built environments can be designed so as to provide visual and tactile reach in 360 degrees, extending Deaf people's awareness and making spatial orientation easier (Weebly 2015). Some examples of strategies to increase one's sensory reach are using mirrors and reflective glass to enable people to see what is occurring in the space behind them (Gertz and Boudreault 2016).

Mobility and proximity

This principle responds to the navigational aspect of experience and making navigating easier. It helps to design space that will enhance social experience, such as walking with your companion while conversing in sign language (Gertz and Boudreault 2016). Also, it is important to design space that will allow signers to move through space uninterrupted (Bauman, H. 2010). When walking and conversing at the same time, signers usually maintain a wide space between them in order to facilitate clear visual communication. They will also scan the surroundings to check for hazards, adjusting their path when necessary. Landscapes, buildings, pathways, and rooms can be designed so that signers can move through space unimpeded (Weebly 2015).

Light and color

Glare, shadows, and backlighting are all examples of poor lighting conditions that can disrupt visual communication. They can contribute to eyestrain, which in turn can contribute to a loss of concentration (Weebly 2015). Gertz and Boudreault (2016) state "Lighting and choice of color paintings need to be considered in a way to optimize conversation in sign language" (294). Bauman and Keane (2010) state that material and ambient qualities can enable communication and way finding.

Acoustics

Deaf people hear various degrees of sounds and can feel sound as vibrations (Gertz and Boudreault 2016). Deaf people use hearing aids or cochlear implants, and different sounds in the environment can be distracting to these people. Hard surfaces in buildings tend to reflect

sound waves which causes reverberation that can not only be distracting but also painful (Gallaudet University Campus Design and Planning 2021; Gertz and Boudreault 2016; Weebly 2015)

The DeafSpace principles outlined above all intentionally support communication issues for those who use ASL. However, only about one percentage of people with hearing loss uses sign language. Lacke (2020) states, “Of the 48 million people in the United States with hearing loss, less than 500,000 – or about 1% - use sign language” (1). Meanwhile, the majority of those who are hard-of-hearing communicate through speech and are in need of the elimination of as many barriers to speech comprehension as possible. DeafSpace design principles privileges those who communicate with ASL and marginalizes people who are hard-of-hearing and dependent on strategies to enhance clarity of sound for speech comprehension and communication in the built environment. As stated above, the Deaf culture and those who are hard-of-hearing have completely different needs in terms of communicating. Maximizing visual access for the Deaf culture is for the purpose of being able to communicate with sign language. However, for those who are hard-of-hearing, visual access is needed for speech reading (formerly known as lip reading) and visual cues, as well as for using communication repair strategies. For those in the Deaf community, glass enables transparency and visual connection. For those who are hard of hearing, glass walls have a less than adequate sound absorbing capability and therefore contribute to inadequate reverberation and speech intelligibility is compromised.

The need for proximity has different meanings. People who are Deaf and use ASL need to be able to see each other while signing. For those who are hard-of-hearing, they need to be close to one another in order to hear one another for such reasons as the distance effect which will be explained below. The need to reduce reverberation and sources of background noise, are for different reasons depending on whether you use ASL or need clarity of sound in order to communicate. I argue that the DeafSpace community has misrepresented the issue that exists with background noise and reverberation. In numerous readings, the principle of acoustics describes background noise and reverberation as being “distracting, even painful especially for individuals using assistive devices” (Bauman and Keane 2010, 86; Gallaudet University Campus Design and Planning 2021; Gallaudet University DeafSpace 2010). To be distracting

means that there is a lack of focus when actually reverberation can distort speech and reduces speech intelligibility, especially for those who are hard-of-hearing.

Environment-Behavior Conceptual Framework

I argue for a more inclusive set of design principles that accommodate people who are hard-of-hearing and have a different lived experience in the built environment than people who use ASL. People who are hard-of-hearing are very dependent on the built environment for speech intelligibility. I propose an interdependent three part environment-behavior conceptual framework for effective communication that prioritizes people and behavioral settings, assistive listening technology, and acoustic considerations in the physical environment.

People and Behavioral Settings

People and the behavioral setting is an undeniably important component in achieving effective communication for a person who is hard-of-hearing. A person who is hard-of-hearing needs the support of the hearing community when it comes to their speech comprehension challenges. People in the hearing community need to be aware and supportive of communication repair strategies and the ‘distance effect.’

Oftentimes, people in the hearing community have a lack of understanding about hearing loss. In particular, aspects of hearing loss such as speech comprehension are often misunderstood. Effective communication repair strategies that are very helpful when conversing, are to face the person when speaking to them, having only one person speak at a time, and ensuring that the hearing person(s) know what hinders good communication such as mumbling, covering one’s mouth with their hand or laptop, and sitting too far away from the person who is hard-of-hearing. White (2009) notes that speech comprehension is improved if the source can be seen, and especially if their lips can be seen and their body language provides additional cues to the spoken words. Having light on the speaker’s face and asking a person to speak a bit louder, slower, and more clearly can also help (Bauman, N. 2010).

“Hard of hearing people understand less and less of the spoken word as distance increases, even when wearing their expensive hearing aids” (Bauman, N. 2015, 1). The distance effect happens when you lose about 6 dB of direct sound for each doubling of distance from the speaker. Ninety percent of people have a high-frequency hearing loss. Because most of the intelligibility of speech lies in the higher frequencies, people with this type of hearing loss have

difficulty understanding much of what is being said. Speech sounds muffled and it is can be difficult to distinguish one word from another. Also, high frequency sounds drop off with increasing distance (Maisel, Steinfeld, Basnak, Smith, and Tauke 2018). Therefore, the closer you are to the person who is hard-of-hearing, the more likely that they will be able to hear you and comprehend what you are saying. An example of something that can help is to have tables and chairs that can be easily moved around, enabling you to make a smaller table when there are fewer people in a meeting (Maisel, Steinfeld, Basnak, Smith, and Tauke 2018).

Assistive Listening Technology

Assistive listening technology includes hearing aids and smart phone applications (apps), FM transmitters and microphone systems, closed captions as well as T-coil induction loops. A T-coil induction loop system uses a telecoil that is present in one's hearing aid connecting it to the loop system in the room. Bauman (2015) states that there are several facts about hearing loss and hearing aids that makes using a loop system viable. The first is that hearing aids do not correct hearing to normal and in fact, they only give back about half of the hearing loss. Even with hearing aids, a person can still have a moderate hearing loss. Another fact is that hearing aids are only effective for distances up to six feet and as mentioned above, speech intelligibility decreases as distance increases. With a loop system, both lower-and-higher-frequency sounds are captured by a microphone before the higher frequency sounds are lost in the air. These sounds are then amplified and streamed to the t-coils in the hard-of-hearing person's hearing aids without having to travel through the air as sound waves (Bauman N. 2015). Another option is to pass a wireless FM microphone around a meeting or classroom and the person who is hard-of-hearing wears the FM speaker which pipes the other peoples' voices directly into the person's ears via a neckloop and the t-coils in the person's hearing aids (Bauman N. 2010).

Acoustics and the Physical Environment

Acoustic considerations that are important for speech intelligibly are enhancing visual connections, and to decrease or eliminate reverberation time, background noise, and sound transfer between spaces. Also, utilizing the appropriate sound absorption materials with the appropriate NRC will be beneficial. A requirement for good listening conditions is adequate reverberation control (Cavanaugh, Tocci and Wilkes 2010). "Excessive reverberation can destroy speech intelligibility" (30). Treasure (2012) states that if there is interference in sending

and receiving sound in a space, communication can't happen. The optimum reverberation time changes with room function. High ceilings help ensure adequate sound quality. Lecture and conference rooms have an optimum time of 0.9 to 1.1 seconds. Auditoriums and general purpose rooms have a time of 1.5 to 1.8 seconds (Grondzik, Kwok, and Reynolds 2005).

Background noise adds another barrier to speech intelligibility (Bauman 2015). This can greatly impact social participation (White 2009). Those with high frequency hearing loss will find it difficult to understand the speech of others when background noise is excessive. A space with high reverberation times will produce too much noise to hear critical information (Maisel, Steinfeld, Basnak, Smith, and Tauke 2018). Controlling background noise will help ensure speech intelligibility and reduced interference from mechanical and electrical systems. Ensuring that heating and air conditioning systems are quiet also supports good acoustic control (Maisel, Steinfeld, Basnak, Smith, and Tauke 2018). Even with the windows closed, wind and traffic noises from vehicles can add to the noise (White 2009). White (2009, 25) "Noise, as opposed to informative sound, is simply sound that interferes with the sound that is desired." Cavanaugh, Tocci and Wilkes (2010) break it down into undesired sounds and desired sounds.

If it is not possible to turn off the source of the background noise, there are two ways to control the noise: blocking sound from travelling from one place to another and absorbing sound (Brooks 2003). There are many opportunities for sound to transfer from adjacent spaces. It can transfer through walls, over the ceiling from other spaces, through doors, through ventilators or louvers above door units, through HVAC ductwork from adjacent spaces, through the light fixtures, from the floor above and from outside, through exterior walls and windows (Nixon 2021). Good specifications could ensure that mechanical equipment and distribution ducts and registers will not generate too much noise (Maisel, Steinfeld, Basnak, Smith, and Tauke 2018).

For noise transmissions between rooms, gaps can be sealed such as under doorways or the cracks around a light switch that allows sound to pass through directly regardless of the insulation in the wall (White 2009). If there is thin glass in the window, it may be necessary to install a second layer of glass much like a storm window (Nixon 2021). Replacing old ineffective ceiling tile with a newer higher performing acoustical tile is also helpful. The higher the noise reduction coefficient (NRC) values of the tiles, the better (Nixon 2021).

The importance of the acoustic qualities of materials to aid in sound absorption cannot be overstated. As Cowan (2000) points out, “When designing any facility for acoustics, the first question that must be answered is, “what is its primary purpose?” The purpose will dictate the desired acoustical parameters and treatments for each space” (51). Absorptive materials include acoustic ceiling tiles, panel and cavity resistors, acoustic panel boards, acoustic plaster, sound baffles, carpeting and drapery (Grondzik, Kwok, and Reynolds 2005; Maisel, Steinfeld, Basnak, Smith and Tauke 2018). A NRC of 0 indicates perfect sound reflection, an NRC of 1 indicates perfect absorption. The higher the number is, the better it is at absorbing sound. An acoustic product with a .95 NRC rating means that 95% of sound in the space is absorbed, and the other 5% is reflected (Nixon 2021). Absorbing materials should also reduce reverberation time to 0.7 seconds for speech. This can vary with different sized rooms (White 2009).

Conclusion

To summarize, we need to acknowledge that DeafSpace design principles privileges those who communicate with ASL and marginalizes people who are hard-of-hearing and dependent on strategies for speech comprehension and communication in the built environment. Unfortunately, a very small percentage of people with hearing loss use sign language, while the majority of those who are hard-of-hearing communicate through speech and are in need of the elimination of as many barriers to speech comprehension as possible. In this paper, I have argued for a more inclusive set of design principles that accommodate people with hearing loss who have a different lived experience in the built environment than people who use ASL. As stated above, I propose a conceptual framework for effective communication that prioritizes people and behavioral settings, assistive listening technology and acoustic considerations in the physical environment.

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Behind the ghetto walls? Life styles of people with disabilities in contemporary Russia

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Perception of disability and of people with disabilities depends on the historical and cultural context and social differences in a particular society. In the past, in Russia, until the mid-20th century a traditional, mainly peasant society, a person with serious diseases or defects preventing him or her from performing daily household functions was viewed as an “extra mouth” to feed (Frolova 2019; Shlyakhtina 2019) with the possible exception of those whose skills could be of use (for example, deaf or retarded persons sometimes became shepherds, blind persons wove baskets. Another exception was the attitude to the so-called fools-for-Christ and silly-hearts who were considered a kind of local saints). In addition to that, such perception is in line with Judeo-Christian ideas of punishment for one’s sin or the sin of one’s ancestors. Russian culture was a local version of the “culture of guilt” (described by R. Benedict back in 1989 (Benedict 1989)), which also had a significant impact on how disabled people perceived their disability.

In the USSR, perception of disability and disabled people was ambivalent. On the one hand, a person with disability who was unable to work was inevitably perceived as a “burden to society”. (Fieseler 2014), a perception still largely shared today. On the other hand, Soviet literature glorified persons who overcame a severe disability and became socially “useful” (Nosenko-Stein 2021). In its early years, the USSR pursued a social policy aimed at involving people with disabilities in community work – in the 1920s, workshops for visually and hearing impaired people, also people with some other categories of disability, were set up where simple manual labor was practiced (making brushes, mending clothes, etc.). At the same time – and it became especially obvious after World War 2 – the policy was to “clear” the streets of Soviet cities of disabled people sending them away to remote special-purpose institutions. In the 1960s-1970s, based on organizations for disabled people (the All-Union Society of the Blind, the All-Union Society of the Deaf), specialized enterprises were created where people with disabilities worked. Work there was also generally fairly simple (assembly of electrical plugs and sockets, work in forge-and-press shops, etc.). Those enterprises enjoyed a serious

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government support (e.g. they were partially or fully exempt from taxes) and could provide welfare payments and benefits to their employees (Nosenko-Stein 2018).

This kind of policy inevitably led to people with disabilities becoming locked in an environment of people of their kind. The situation was even more exacerbated by the perceived Other body. Not infrequently, Other corporeality was an object of all sorts of negative clichés and stereotypes, including fear, disgust, desire to distance oneself from it (Bolt 2014; Nosenko-Stein 2017). Such stereotypes manifest themselves especially strongly in respect of mentally and psychically impaired persons as Other corporeality in those cases is often accompanied by secretions, odors, sounds that a person is unable to control (Klepikova 2018). People with physical defects may also cause such emotions – this is evidenced both by autobiographical texts written by people with disabilities and by fiction, especially by mass fiction books reflecting mass stereotypes and fears (Garland Thompson 1997; Bolt 2014; Nosenko-Stein 2021).

This paper is a brief essay on how what I call a “disability ghetto”, a kind of closed socio-cultural environment in which part of people with disabilities exist, has occurred. An attempt is also made to describe the attitude of people with disabilities to this phenomenon.

Sources and methodology

In my research I use various sources. One of them is my field materials – the texts of in-depth interviews that I took of persons with disabilities and heads of organizations for disabled people in 2014-2021 in different Russian cities (Moscow, Nizhniy Novgorod, Smolensk, Kislovodsk, and Archangelsk). Those cities in the European part of Russia were selected as they represent mega cities (Moscow, Nizhniy Novgorod), medium-size regional centers (Archangelsk and Smolensk) and relatively small cities (Kislovodsk). Chosen as informants were people with congenital and late-life disability – people with sensory disorders (vision, hearing), musculo-skeletal system disorders (these are often disorders caused by various injuries), and also neurological diseases (cerebral palsy). I found informants in various organizations for disabled people and also using the “snowball” principle. I have selected 12 biographical interviews for this paper reflecting the experience of other life, a life in a closed community or outside it, and one expert interview touching upon the issue under investigation. Interviews lasted from one to two and half hours and were voice recorded (in certain instances interviews were recorded via Skype or, in case of hearing impairment, for example, via e-mail). These are also texts of

several autobiographies written by persons with disabilities in the post-Soviet period and reflecting life experience and life styles of people with different categories of disability.

Life in a “parallel world”²

People with congenital diseases or diseases acquired early in their childhood leading to disability, often at a pre-school and then school age experience the feeling of loneliness. Rubén Gallego (the grandson of the General Secretary of the Spanish Communist Party who was born in the USSR in 1963 with a severe form of cerebral palsy and put to a special home for children) felt it very early in his life. He wrote about it in his autobiographical notes: “At eight years of age I realized one very simple idea. I am alone and not wanted by anyone <...> I envied Quasimodo. People looked at him with pity and disgust as they looked at me, but he had arms and legs” (Gallego 2004).

The feeling of loneliness and their own otherness is experienced even by those children who grew up in families; with them, the feeling of loneliness paradoxically combines with the feeling of being overprotected. Hyper-protection has been frequently mentioned to me by heads of various organizations for disabled people who said that parents often raise their children in a way that they do not develop any independent-living skills and are incapable of performing simplest actions towards that. The head of a “cell” in the All-Union Society of the Blind said:

I have recently talked to this kind of a mum. Just imagine, her boy is 18 and she laces his boots for him! – “Oh, but he doesn’t see!” – “And what of it? - I tell her. “He needs to be able to do everything he needs. You won’t be around all his life”. But it’s no use saying it to such people. (Nizhniy Novgorod 2015)

Such hyper-protection increases the child’s isolation from “normal” peers, which, in turn, exacerbates the feeling of loneliness and even of being an outcast that will be there for a long time or forever. Yulia V., 28, life-long disabled (cerebral palsy), studied in a special school for children with musculo-skeletal system (MSS) diseases:

I remember once taking a look in the direction of children who sailed toy boats in a puddle and got besmeared all over doing that. My mum noticed it, smacked me on the backside and shouted something like ‘the pigs are frolicking here unattended, you will never ever have anything to do with them!’ – “Why never ever?”- I asked. Mum said they had other life and other interests. I felt hurt about having some other way of I life. (Moscow 2018)

Victor V., 42, life-long disabled, MSS disease, does not work, lives with his mother:

² The phrase “parallel worlds” is taken from the title of a paper referenced here (Phillips 2018).

My mum told me that in my early childhood she simply had not dared to let me play with other children. As a result, I never attended a kindergarten. I didn't have friends in the neighborhood, when I went out for a walk, it was always with my mum holding me by the hand. Later, I felt all my life that I was an outcast." (Nizhniy Novgorod, 2017)

Such children develop a feeling of their 'otherness', isolation and impossibility to belong to the world of normal people and it stays with them for many years. Those who went to special schools gradually develop a circle of Own people who they mainly communicate with, make friends with and pass their leisure time with outside of school. Yulia V. mentioned above: "I could certainly study only at a special school; how could I be at a regular one? I'd have been henpecked there. Approach to children at my school was normal." (Moscow, 2018).

In the latter case, as Yulia mentioned on several occasions, the situation was exacerbated by Other corporeality (involuntary limb contractions, peculiar speech causing children's and adults' unfriendly curiosity). Other corporeality is a cultural marker differentiating Other ones from normal ones. Isolation from the world of normal ones is much driven by going to special boarding schools which existed and continue to exist in mega cities (when it is difficult for parents to take their disabled child to a school located far from home and pick him/her up from there after classes). After finishing boarding schools, many former school children join organizations for disabled people where they spend their leisure time (excursions, concerts, festive events), which deepens "ghettoisation", sometimes voluntary, of such people.

Vladimir Z., 63, life-long disabled (impaired vision), a history teacher at a school, was very enthusiastic: "Our All-Russia Society of the Blind is really great! There are so many interesting things there and people are so warm. ...A place to rest my mind" (Moscow, 2015). Currently those organizations, no longer enjoying government support, have lost their former attractiveness for people with disabilities and turned mainly into leisure centers (Nikonova 2018).

Later, some people with disabilities continue to study trying to get vocational or higher education, which in the past two to three decades has become more complicated (Voronin 2018). In Russia there still exist special secondary education institutions where people with different disability categories are trained (visually impaired masseurs, deaf librarians, etc.) (Bolshakov 2017). Being in such educational institutions also deepens the trend towards separation of people with disabilities.

Bairamkis, 48, life-long disabled (impaired vision), masseur, studied at a remedial school, then at the Kislovodsk Medical School for the Visually Impaired People:

After school where all of us were more or less the same, I continued for another two years in Kislovodsk. Everybody was like that there and we kind of stewed in our own juice. <...> When I got married and moved to the city of Kemerovo, not only did I feel self-conscious, I was awfully inhibited and uncomfortable... For roughly 12 years I had lived in a circle where everybody was blind or partially sighted. And when we left that environment, when we went to work, I felt like a disabled person, I felt bad, I cowered. I felt my disability, my inferiority (Moscow, 2015).

Thus, a “disability ghetto” begins to be formed early in disabled people’s lives. If they happen to get outside it, they often feel like Strangers, like people who are “worse” than those who are normal. They feel psychologically comfortable among people of their kind, while from others they feel wariness and sometimes a negative attitude. Lidya N., 38, disabled from cerebral palsy, university background, does not work:

When after school I was enrolled at a university, I immediately felt that I was being looked at in a kind of peculiar way. No, they didn’t bully me. Nothing of the kind, I was simply very much unlike all the others, I was a freak to them. ... I felt it when I was a child, too, but at school I was among kids of the same kind, in the street, though, it was different. Sometimes people wouldn’t just stare at me, they would point their finger at me. ... I remember literally throwing a tantrum crying: “I want to be like everybody else, like everybody else, like everybody else.” (Archangelsk, 2017)

Another reason for ghettoisation of people with disabilities is the fact that such people tend to massively select certain universities for their higher education. For example, many go to the Moscow State University of Psychology and Education to become psychologists, the State University of Culture trains librarians and bibliographers, the Russian State Social University trains social workers, etc. People with disabilities find it much more difficult to find a job as a result of being overtly, and more frequently covertly, discriminated against. Many of them fail to get employment. (Lazoukova, and Seletkova 2018; Nosenko-Stein 2018).

Not infrequently, life-long disabled people eventually stop striving to break away from the “ghetto” and prefer to continue to be with their own kind, including dating them, marrying them, etc. The low status of people with disabilities discourages a considerable part of them from living in such “ghettos” – they do not want to join “disabled” organizations because they do not want to belong in a low-status community.

For example, Larisa G., 54, visually impaired, at the time of the interview was temporarily unemployed: “I have never felt inferior. You see, there has never been any talk of disability in my family. I was brought up not to be inferior” (Moscow, 2017). Larisa was not a member of the All-Russia Society of the Blind and her perception of people with disabilities as “inferior” fairly well characterizes her reluctance to belong with them.

Life beyond the watershed³

The “disability ghetto” is also avoided by those who became disabled as adults as a result of an injury, a progressing disease, wrong medical treatment, etc. For them, identifying themselves with the “disability ghetto” does not only mean joining a low-status community, it is a kind of confirmation of their final passage to the netherworld (Nosenko-Stein 2020), a confirmation of their othering, of acquiring the status of Other, “worse” people. In her autobiographical notes, Irina Yassina described the feelings she had after the verdict of a diagnosis had been passed on her (she is the daughter of a well-known Russian economist, Yevgeniy Yassin, in the past worked in the banking system, at the age of 35 was diagnosed with multiple sclerosis, a neurological disease leading to a severe disability): “My future seemed more terrible than death to me, it meant helplessness, dependency, and loneliness. I feared waking up” (Yassina 2011).

As has already been said, many organizations for people with disabilities have now turned into leisure centers, therefore people with late-life disability do not see any sense joining them – there is no real possibility of getting help with employment, no chance of making friends or meeting future spouses as horizontal links have already been formed by those life-long disabled people who joined the organizations a long time ago.

That is the reason why people with late-life disability, for whom its appearance is usually very painful (quite often perceived as a personal disaster), try to avoid getting into the “disability ghetto” preferring loneliness and choosing either active life strategies or, on the contrary, the path of self-isolation. Vladimir N., 45, hearing loss (lost his hearing at 42 as a result of a post-flu complication), was a chemistry professor at a university in Moscow, had to quit after the diagnosis, lives with his wife and son:

In the beginning, I thought I’d lose my mind ... My job, my friends, my family – who’d need me crippled like that, - I thought. Not hearing anything, everybody having to write to you. ... Then I began getting used to it. I had to part with my job and now spend a lot of time in our summer

³ The title of this section is a paraphrase of the title of a chapter in A. Grafov’s autobiographical book “Notes of a Blind Person” (2009).

house <...> It's also life, isn't it, only kind of detached from everybody. Honestly, I thought I'd go off my chump <when I lost my hearing>. I was like in a cotton-wool cocoon, rather like in a sound-proof chamber. <...> How can I work - I can't give lectures, can I? <...> It was very hard at home, too. <...> Bad thoughts occurred – well, you understand... Even now I try to spend more time in the summer house in the countryside – apple trees don't need to be spoken to.

– Did you try to turn to the All-Russia Society of the Deaf?

– No. Well, my mother-in-law called them. They say: “Please, join and be our member”. She asks: “What can you help my son-in-law with?” They said they organize parties, hold meetings. What do I need all that for? (Moscow, 2018)”

Maxim V., 37, became disabled at 32 as a result of a car accident, now in a wheelchair; before the accident was a sole trader, was married, has a daughter; currently does not work, lives alone:

At first, it was more than just hard – I didn't know where I was and what had happened to me. But at that time some of my friends visited me, my wife was still with me, and my daughter... Now I'm like inside a cannon ball, I don't have anything. Just the internet, my little window into the world. But then who shall I write to... Who could care about my problems? You know, I sometimes simply write letters and email them to fake addresses. (Nizhny Novgorod, 2015)

In other words, those who become disabled as adults perceive their new status as a ruin of their life passing from their former world and status (rather, statuses) to another world and a lower status.

Such people for a long time - sometimes for their whole life - remain in a liminal state much written about by V. Turner, R. Murphy et al (Turner 1983; Murphy et al. 1988): “...they do not have a status, <...>. Their behavior is passive or humble; <...>. It is as though they are being reduced or ground down to a uniform condition to be fashioned anew and endowed with additional powers to enable them to cope with their new station in life” (Turner 1983: 81).

Some people with late-life disabilities join different disabled people's organizations and communities, but, according to heads of such organizations and informants themselves, they usually remain “passive members” or simply are on their membership lists.

Svetlana M., 36, with serious MSS disorders resulting from a car accident), works from home:

I always wanted to do something artistic, something related to beauty. But my parents thought it was unreliable, that there wasn't much money in it. And I listened to them and went to a sales vocational school. <...> And after all that (Svetlana means the accident and subsequent disability) I began making all sorts of trinkets – beads, pendants, earrings. First for myself and friends, then for sale. Well, you know, maybe it's really true, after all, that every cloud has its silver lining (smiling). And then, one wants to make at least some extra money, pensions in Smolensk are low. <...> - Did you try to turn to the All-Russia Society of Disabled People? – I did. I am even registered with them, or whatever it is called. But they didn't help me in any way Well, they do hold meetings but I can't physically get there anyway.” (Smolensk 2016)

Walls around the ghetto

The “disability ghetto” is a construct of normal people. The leitmotif of a great many oral stories is embarrassment and even fear felt by people at large towards people with disabilities (Nosenko-Stein 2017). These emotions may take the form of concern for disabled people's physical or mental disorders ('he will fall down', 'he will break something,' 'he will not manage'). Very often people do not know what is the right way to help a disabled person in this or that situation and whether they should be helped at all. As a result, normal people want to distance themselves from and avoid people with disabilities.

Elena N., 37, visually impaired, university education, lawyer, at the time of the interview did not work:

It has always seemed to me that it was nothing but fear, people don't know and they are scared right away – what if some additional efforts will be required from them with this person. That's the impression I get -what if I start making claims, what if I want a free ride on their backs. I have always felt that way. (Moscow, 2018)

Those impressions are not groundless. As has already been said, in the USSR before and in many post-Soviet countries now, a person with disabilities has often been perceived as a “burden to society”. Alexander Suvorov, a deaf-blind poet and scholar has many a time written about such a perception. In his autobiographical book he cites the words of a teacher from a boarding school for deaf-blind children:

That's just what I wanted to speak about. A lot has been invested in those children, very much indeed. And what can they give back? That's the first thing to think about. The state has been generous to them and will continue to be – they are domiciled in Moscow, they have a degree,

they have been provided with housing. What for? They cannot give anything back to the state, nothing in return, zero return.” (Suvorov 1996)

To add to that, people want to distance themselves from those who in a given society are stigmatized due to their low status, and people with disabilities are one of the most stigmatized social groups (Goffman 1963; Iarskaia-Smirnova 2001). The situation is similar to what G.W. Allport wrote about several decades ago describing the mechanism of distancing from and avoiding Jews in Nazi Germany (Allport 1954). That is why people with disabilities (even life-long disabled persons “integrated” in the life of a disabled community) sometimes want to distance themselves in appearance from the “disabled status.”

Anastasia K., 28, loss of eyesight (was gradually losing her eyesight as a result of progressing macular degeneration of retina until final loss happened at the age of 17). Anastasia graduated from a medical vocational school for the blind and works as a masseur in the city of Kislovodsk: “How can we be disabled? We are not disabled, are we? Disabled is someone who cannot attend to oneself, a vegetable. As for me, I work, do everything myself. We are not disabled, we are people with limited abilities, that’s what we are” (Kislovodsk, 2017).

Such people, usually those who opted for an active attitude to life, do not want to live in the “disability ghetto” not only because they are reluctant to find themselves among members of a low-status community but also because they do not see any sense in the mere existence of such communities.

Maria, 32, cerebral palsy, a post-graduate degree in pedagogics, works at the Moscow State University of Psychology and Education. When asked if she was a member of the All-Russia Society of Disabled People, she answered: “No, I hadn’t joined it before I came to Moscow <Maria used to live Stavropol>, somehow hadn’t got round to it. I don’t know what for. <...> Neither have I got round to it in Moscow yet. Maybe if I understand that it’s necessary, I will” (Moscow, 2021).

Conclusions

The existence of the “disability ghetto” leads, on the one hand, to normal people lacking objective knowledge about disability and about real problems of people with disabilities. This results in prejudice, negative stereotypes and clichés, stigmatization deepening in mass consciousness. At the day-to-day level, in turn, this leads to distancing from and avoiding those who are bodily Other, hiding – and sometimes not hiding - the feeling of disgust and fear.

In a number of cases people with disabilities, especially with a late-life occurring disability or relatively “easy” disability, also want to distance themselves from those who have completed the “rite of passage” and who are very low on the social ladder. I have already written elsewhere that for people with a late-life disability a medical diagnosis confirming their new status is the beginning of a kind of rite of passage not only from one status to another but also from one world to another (Nosenko-Stein 2020). Stigmatization of people with disabilities, serious difficulties with their psychological, daily-life, and social rehabilitation, almost total lack of professional re-training and discrimination when being hired lead to people with late-life disability finding themselves in a vacuum. Auto-stereotypes of otherness, perceiving themselves as a Stranger among Strangers also contributes to their separation from other people (the price they pay for refusing to “live in a ghetto”, in practical terms it often leads to serious difficulties with adaptation and integration in society).

On the other hand, - and that is typical of many types of ghettos (take for example Jewish ghettos where the gate in the wall surrounding them was locked for the night from inside) - some people with disabilities (especially life-long disabled persons and persons with a severe disability) are not at all eager to go out to the “great wide world” feeling psychologically more comfortable among those of their kind, Own people, where they can easier find the necessary information or help without running into situations of being avoided or directly insulted. That is characteristic not only of people with disabilities but also of representatives of many low-status socio-cultural groups. In cases when internal relations and elements of support develop or already exist inside such groups, the situation of a socio-cultural ghetto may arise.

Normal people are happy with the “ghetto” situation as it makes it possible to have social control over people with disabilities and take decisions not caring much about their opinion.

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Judging the Body: Disabled Voices in the Ancient Greek Lawcourt Lysias 24: contents, contexts, and previous readings

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This paper aims to showcase how one person's disabled identity—that of the unnamed defendant of the legal speech Lysias 24 (conventionally titled *For the Defence of the Pension of an Invalid*)² who was accused of faking his disability and low income to obtain social security payments—interacted with wider conceptions of citizen identity in Classical Athens. This paper brings an intersectional approach to this speech, which touches on multiple aspects of an ancient disabled person's lived experience, including citizen identity: by viewing the speaker's disabled identity as shaped by his economic status (and vice-versa), this in turn shapes the way we can interpret his experience of citizen identity, as well as his sense of belonging to a citizen body. Recent approaches in critical theory have laid bare the ways in which class and disability can shape a person's identity and relationship to citizen status.³ In viewing an ancient text through an intersectional lens, I aim to emphasize the complexities of ancient lived experiences of disability as a way to gain a more nuanced reading of elements of ancient Athenian citizen identity.

Lysias 24 features the defence of a man accused of defrauding the Athenian administration to obtain a support payment of one *obol* a day.⁴ The speech exists in the context of the annual scrutiny that all recipients of benefits had to undergo in order to remain eligible and was part of a wider Athenian system of checks and balances known generally as *dokimasia*.⁵ Though such a review was probably just a formality, the payment could be brought into question should someone bring forward a reasonable complaint. In this case, the man stands accused of defrauding the system by faking a disability and claiming to be poor when he had been seen practicing a trade: by the fourth century, eligibility for the payment was determined by a complete inability to work and ownership of less than three *minas* (Arist. *Ath. Pol.* 49.4).

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² Martha Lynn Rose, "Ability and Disability in Classical Athenian Oratory," in *Disability in Antiquity*, ed. Christian Laes (London: Routledge, 2020), 139.

³ Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (New York City: Verso Books, 1995). Nirmala Erevelles, "(Im)Material Citizens: Cognitive Disability, Race and the Politics of Citizenship," *Disability, Culture and Education* 1, no. 1 (1996): 5–25; "Disability and the Dialectics of Difference," *Disability and Society* 11, no. 4 (2002): 519–37.

⁴ At the time, an *obol* could roughly purchase 3L of wine. See James Davidson, *Courtesans and Fishcakes: The Consuming Passions of Classical Athens* (London: Fontana Press, 1998), 59–60.

⁵ The process of *dokimasia* was employed for a variety of public offices and payments. See Gabriel Adeleye, "The Purpose of the *Dokimasia*," *Greek, Roman and Byzantine Studies* 24 (1983): 299.

The accuser has argued that the man is lying about being *adunatos* (loosely translatable as “unable”),⁶ and has brought forward a number of allegations to prove this: that defender is not disabled, as he is capable of riding horses; that he is not poor, as he owns a workshop and seems to be practicing a trade (which is further proven by the company he keeps: rich men); and, finally, that the nature of his character is duplicitous and immoral, as is that of the people with whom he chooses to associate himself.⁷

In the process of deconstructing each point raised by the accusation, the speaker makes numerous references to his day-to-day life, his access needs, and his use of mobility aids, as well as his economic status. For example, he argues that the horses he is accused of owning, a sure sign of wealth, are borrowed, and that they are as necessary to him as his other mobility aids:

For it seems clear to me, members of the jury, that whoever finds themselves in this situation, seeks to live in the easiest way possible, and with the least pain. So I have been doing this [borrowing a horse] as a way to be able to make longer journeys more easily. (...) When [the accuser] sees me using two crutches, even though others use only one, he does not suddenly decide I am able-bodied. Then why, as soon as he sees me riding a horse, does he decide I am no longer disabled? I need the one just as much as I need the other (Lys. 24.10-12).

Similarly, the speaker's rebuttals of accusations of ill character are recontextualised within a self-narrative of disability and poverty:

I know, members of the jury, that you must correctly discern between those who are capable of acting with *hybris*, and those who are incapable of doing so. It is unlikely for poor men to act outrageously, but it is far more likely for those who have more than what they need. Nor would someone disabled act with no remorse, and those who can rely on the full strength of their bodies are much more likely to ... (Lys. 24.15-16).

⁶ For a discussion of the meaning of *adunatos*, and its implications for a more generalised ancient disabled identity, see Martha Lynn Rose, *The Staff of Oedipus: Transforming Disability in Ancient Greece* (Ann Arbor: The University of Michigan Press, 2003), 96–97. and Carlo Delli Noci, Friederich Stiefel, and Vincent Barras, “De l’invalidite a l’adunatos: Reflexions Sur l’invalidite et Le Trouble Somatoforme Douloureux,” *Revue Médicale Suisse* 13 (2013): 365–68. For disability assistance payments in particular, see Arthur R. Hands, *Charities and Social Aid in Greece and Rome*, Aspects of Greek and Roman Life (London: Thames and Hudson, 1968), 10, 172. and Matthew P. J. Dillon, “Payments for the Disabled at Athens: Social Justice or Fear of Aristocratic Patronage?,” *Ancient Society* 26 (1995): 27–57.

⁷ Christopher Carey, “Structure and Strategy in Lysias XXIV,” *Greece & Rome* 37, no. 1 (1990): 45.; Rose, “Disability in Classical Oratory,” 140–41; Andrew Wolpert and Konstantinos Kapparis, eds., *Legal Speeches of Democratic Athens: Sources for Athenian History* (Indianapolis: Hackett Publishing, 2011), 65.

In both these passages it is clear how the speaker's sense of identity is articulated through his disability and his poverty: both of these aspects actively influence his life, his outlook and what he views himself as capable of being and doing. Both of these are seen as defining aspects of who he is as a person. And both, as we will see below, have a direct bearing on his own identity as a citizen of Athens. Where the speaker justifies his using of horses, he does so because he cannot even afford a mule as a mobility aid. This is because he finds it difficult to work, a fact exacerbated by his disability: "I already have difficulty practicing [my craft] and am not able to hire someone to do it for me" (Lys. 24.6). Whereas a horse in the Ancient world would typically be a status symbol, a proof of wealth, in this case it is the opposite, representing the speaker's poverty (as he is unable to buy a mule) and his impairment (needing an additional mobility aid alongside his crutches).

And yet, much of the previous scholarship on Lysias 24 has focused on only one of these aspects: the speaker's economic status, and Athens' class tensions as a whole.⁸ These issues of class have often taken centre stage, exemplified by the tension between the Athenian elites, owners of horses, and the "common" democratic people, a tension which throughout the speech co-exists with the jealousy that poorer members of society seem to hold towards those better off than them: "these wicked men who have lost their fortune, and plot against those who still keep it" (Lys. 24.19).⁸ This is not to say, however, that these previous analyses are without merit. They offer an important reading of the economic contexts in which the speech was written, and it is true that Lys. 24 offers a viewpoint rarely seen in most, if any, other legal speeches: that of a poor person, as previous analyses have rightly pointed out.⁹ Many of these readings, such as Dillon, justly place the speech within the context of wider tensions that existed between the democracy and its elite. But such readings, in treating the speaker's disability as an afterthought, or as secondary to his poverty, deny the representation of the speaker's life its true nuance and complexity: as we've seen above, the speaker of Lys. 24 defines himself very clearly along two lines: disability and poverty.¹⁰ In this speech, class status and impairment are closely

⁸ For an overview of class tensions in Athens (with primary sources), see David Konstan, *Greek Comedy and Ideology* (Oxford: Oxford University Press, 1995), 74–90. and Josiah Ober, *Mass and Elite in Democratic Athens. Rhetoric, Ideology and the Power of the People* (Princeton: Princeton University Press, 1990), 208–9.

⁹ Wolpert and Kapparis, *Legal Speeches*, 65.; Wilfred E. Major, "Democracy, Poverty, Comic Heroism and Oratorical Strategy in Lysias 24," in *Comic Invective in Ancient Greek and Roman Oratory*, ed. Sophia Papaioannou and Andreas Serafim (Berlin: De Gruyter, 2021), 260–61., as well as Carey, "Structure and Strategy" and Rose, "Disability in Classical Oratory."

¹⁰ On Lysias' tendency to create "personas" for his defendants, see Edith Hall, "Lawcourt Dramas: The Power of Performance in Greek Forensic Oratory," *Bulletin of the Institute for Classical Studies* 40 (1995): 49–50.

intertwined.

Autochthony and the performance of citizenship

Marxist and materialist readings of disability have emphasised the ways in which, when taken in concert with ideas of productivity and socio-economic history, the definition of *disability* itself is subject to shift depending on these broader contexts.¹¹ Such readings are, as the above definition posits, closely connected to those “historically specific economic structures”¹² within which a disabled person lives their life. The one cannot be defined without the other, as labour is defined by who is capable to undertake it, and this capability (or lack thereof) is defined by the amount of labour a person can or cannot perform.

When we apply this reading to Lys. 24, it becomes clear how the defendant's disability and class cannot, and should not, be taken separately, or as subordinate the one to the other—nor, as pointed out above, are they seen as separate within the speech itself. This duality is possible thanks to Athens' somewhat uncommon (for the time) definition of citizenship. Though the defendant is, per his own admission, unable to produce enough income to support himself, this does not preclude his belonging to the citizen body, and yet his being *adunatos* still determines how he relates to the citizen status this belonging grants him. Unlike many other ancient Greek city-states, Athenian citizenship is *inherent* to an individual and relies first and foremost on a codified recognition of one's *genetic* belonging to the Athenian *demos*. The Perikleancitizenship law of 451 BCE is what codified the genetic exclusivity of Athenian citizenship, defined by a common autochthonous origin: that an Athenian citizen is someone who can prove Athenian parentage on both sides, that is, someone who is born of both an Athenian father *and* an Athenian mother.¹³

The myth of Athenian autochthony is, at its core, a myth about Athenian exceptionalism. Ancient Athenians pride themselves in having never emigrated from elsewhere into Attika, therefore seeing themselves as having an exclusive claim to the land their city had been built upon. It is the myth used by Athens to reinforce the ideology of its own supremacy, and to

¹¹ Erevelles, “Dialectics of Difference,” 525; Brendan J. Gleeson, “Disability Studies: A Historical Materialist View,” *Disability and Society* 12, no. 2 (1997): 191.

¹² Erevelles, “Dialectics of Difference,” 525.

¹³ Nicole Loraux, *Born of the Earth: Myth and Politics in Athens*, trans. Selina Stewart (Ithaca (NY): Cornell University Press, 2000), 19–20; Susan Lape, “Solon and the Institution of the ‘Democratic’ Family Form,” *The Classical Journal* 98, no. 2 (2003): 129; Josine H. Blok, “Perikles’ Citizenship Law: A New Perspective,” *Historia*, 2009, 141–70. This meant that, should a naturalised non-Athenian marry an Athenian, their children would be considered Athenian citizens.

legitimise its own power by identifying a continuity of descent, from mythical kings to contemporary Athenian citizens.

It is also the mechanism which allows the speaker of Lys. 24 access to his social security. Citizenship can be defined as an interconnected system of rights and duties, determined by *timē*, that is, honour: what one did in service of their city shaped what the city did for them, what honours it conferred them shaped what honour they brought to it and their fellow citizens, and vice-versa.¹⁴ As such, ancient Greek citizenship can be generally read as performative, as evidenced for example when looking at the criteria necessary for Spartan citizenship, which ranges from physical (being able to survive the *agōgē*, the youth training programme) to economical (having enough money to support the common mess halls). In Athens, however, as having Athenian parents is the only real criteria for being a citizen, the performativity of citizenship takes a step back, and systems come into place to ensure that even those who cannot fully perform the duties expected of citizens do not risk *atimia*, a loss of citizen status. Class is therefore not a determining factor when speaking of Athenian citizenship, strictly speaking. *Timē* is still accessible to poorer citizens, if nothing else in virtue of their genetic status as Athenians. In a similar fashion, it is also accessible to disabled (male) citizens.¹⁵

This is the material context of citizenship within which the defendant of Lys. 24 is made to articulate his disabled identity. It is evident from his words that he considers himself disabled: the parameters of Athenian society are such that it allows for a category, the *adunatai*, which it recognises as being “other” in virtue of its inability to wholly fulfil the requirements of citizenship, yet is still part of the citizen body despite this.

Conclusions

It is not a coincidence, then, that poverty and disability are the axis upon which the defendant seems to build his own identity, and the criteria according to which the city of Athens itself would deem him *adunatos*. As his disability influences his class status, and his class status influences the support and mobility aids he can rely on and through which he must negotiate his day-to-day interactions with other citizens and the space he lives in, so do these two elements comprise the criteria along which he is, or isn't, deemed “unable.” In analysing these two

¹⁴ Mirko Canevaro, “I Diritti Come Spazio Di Socialità: La *Timē* Tra Diritto e Doveri,” in *Dike. Ovvero Della Giustizia Tra l'Olimpo e La Terra*, ed. Alberto Camerotto and Filippomaria Pontani (Milano-Udine: Mimesis Edizioni, 2020), 163.

¹⁵ Matthew P. J. Dillon, “Legal (and Customary?) Approaches to the Disabled in Ancient Greece,” in *Disability in Antiquity*, ed. Christian Laes (London: Routledge, 2016), 175–77.

elements as they are articulated within the Athenian model of citizenship, unconstrained by issues of performativity as much as it is confined by strict genetic definitions, we are able to see how they are important modifiers to an otherwise stable definition of Athenian citizen. And, most importantly, we are able to see how the one cannot be read as independent from the other, but rather as both contributing to a person's sense of identity and belonging to his community, both playing important roles in the ways in which their identity articulates itself and is expressed. It is, after all, to this common belonging that the defendant appeals to in the concluding remarks of his speech: “Do not deprive me of the one thing that I am allowed by my homeland. Do not take away that which all of you have already commonly given me, all because you have been convinced by this one man” (Lys. 24.22.)

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The Intersectionality of Disability, Religion, Ethnicity, and Gender: Muslim Arabs in The United States

Majd Subih¹

Introduction

Identifying the Problem

Some have criticized disability identity discourse as dismissive of intersectionality and context. Identities are flexible, contextual (Gomzina, 2012; Evans, 2017), and in a constant state of negotiation (Riddell & Watson, 2014). This understanding of identity urges disability researchers' to not examine disability identity in a void and assume its universality, rather to pay attention to the individual's culture(s), context(s), experiences, and how they make and/or negotiate their identities and meanings of the self. There is a need to consider the individual's experiences that are not only influenced by the social and physical environment, but also by the unique materiality of the individual's body (Evans, 2017).

In the field of disability studies there are two broad approaches to understanding disability identity: one that calls for a collective identity and the second calls for an intersectional identity. The first approach calls for a shared or collective identity that embodies the individual's impairment. This approach came about as a movement to counter and resist the oppression faced by disabled individuals. As Johnstone (2004, p. 1) highlights, "{t}hroughout the twentieth century [...] collective or group identity has been used as a descriptor and/or political tool for groups typically residing at the margins of society. [...] a tool for building common culture and empowerment." In other words, disability as a collective experience helped identify and expose exclusion in this context. Furthermore, such collective identity helped in creating a disability community. Yet as important as this approach to disability identity is, it loses the nuances and complexity of disability experiences. It assumes that disability identity is the foundation and the driving wheel for the whole identity of individuals with disabilities (for example see Dunn and Burcaw, 2013), and ignores that not all disabled individuals include their impairment in their identity construction. Some scholars in the field argue that in claiming a positive identity when having a disability, the individual must adhere

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to a bullet pointed list (see for example Oliver, 1996; Dunn & Burcaw, 2013; Putnam, 2005). Such an approach views disability identity from a positive/negative dichotomy which can be problematic to one's understanding of their impairment and self. It reduces the complexity of the disability experiences and assumes that disability identity exists prior to language and is simply 'marked' or 'reflected' (Watson, 2002, p. 523).

The second approach to disability identity emphasizes the intersectionality of identities and experiences. Intersectionality is an analytic framework that identifies how society's interwoven power systems affect the most marginalized members of society and considers these relationships when promoting social and political justice (Brittney, 2015). Thus, when analyzing identity discourse with an intersectional approach, Davis (2006) urges the avoidance of categorizing many identities under one. Such categorization can alienate the many identities one claims. Instead, we need to analyze the different "ways by which social divisions are concretely enmeshed and constructed by each other and how they relate to political and subjective constructions of identities" (p. 57). In other words, Davis (2006) stresses the importance of recognizing the interaction between one's identity and the context they are in at a specific moment. Furthermore, this approach to identity views the individual as a whole, as the many components of themselves are connected to and influence each other. Thus, it makes it harder to claim a common identity based on shared experiences, as such experiences are unique, multilayered, and complex in essence.

Disabled individuals are often viewed to have similar "views, experiences, and priorities, regardless of gender, age, cultural background, sexual orientation, socio-economic status, religion, and other categories of difference" (Goethals, et al., 2015, p.75). Yet the immense diversity of disabled individuals begs otherwise. The disability studies field is dominated by narratives by and about White and Western people (Bell, 2010; Hladki, 2020; Ineese-Nash, 2020). That is, its epistemological underpinnings are based on Eurocentric views that favor theory from the global North (Nguyen, 2018). Such a lens obscures the experiences of disabled people who do not belong to those groups. Consequently, an increasing number of disability studies scholars are calling for the adoption of an intersectional approach that recognize the existence of different systematic discriminations, how they interact with one another, and pose distinct challenges for individuals and communities affected (Goethals, et al., 2015). Within this context, Goethals, et al. (2015, p 75) pose an imperative question: "...which persons with

a disability tend to be excluded from current research projects?” In other words, whose experiences, perceptions, and understandings of disability are we ignoring?

Scholars argue that the experiences of disabled, Muslim, Arab men and women in the United States are neglected (Habayeb, et. al., 2020; Hernández-Saca & Kahn, 2019; Al Khateeb et. al., 2015; Zidan & Chan, 2019). This is also the case in the Arab world (Gharaibeh, 2009; Al-Khateeb, et. al., 2020). Welcoming diverse understandings of disability will offer more richness to the field and will ultimately help inform and influence policy and contribute to the field of disability studies. As such, this review aims to investigate the complex intersectionality of disability, religion (Islam), ethnicity (Arab), and gender (females and males) among this population in the Arab world and the United States.

Theoretical and Conceptual frameworks

Theorizing Identity

The concept of identity is complex in nature. A person’s identity can be easily recognizable; nonetheless, it is not precise nor easily defined (Parry, 2002). Huntington (1997) states, identity “is defined both by common objective elements, such as language, history, religion, customs, institutions, and by the subjective self-identification of people” (p. 43). The process of defining one’s identity requires a person to appropriate a flexible view, as identity is constantly changing, flexible, fluid in nature (Evans, 2017; Holliday, 2010), ambiguous, unstable (Gee, 2001), contextual (Evans, 2017), and in a constant state of negotiation (Riddell & Watson, 2014). Hence, answering the question ‘who am I?’ is never an easy task. In psychology, the term “identity” is often used to refer to conceptions of the self, expressions of individuality, and accounts of group affiliation (Dunn & Burcaw, 2013). Identities define individuals because they contain traits, personal characteristics, roles, and one’s ties to social groups. They can be focused on one’s past (what was true once), the present (what is still true), and the future (our wishes, expectations, and fears) (Dunn & Burcaw, 2013).

Gelfand (2018), a cultural psychologist, adds, identity is a “symptom” of culture. Watson (2002) states “self is the product of culture, providing individuals with an identity” (p. 511). Culture and human psychology “make each other up” (Morling, 2016, p. 694), and culture shapes human behavior and mind. Identities are not created in a void, rather they are contextual; the culture surrounding us plays a role in the identities we claim and negotiate. As Holliday (2010) argues, cultures are part of one’s identity. This understanding of identity urges disability

researchers' to not examine disability identity in a void and assume its universality, rather to pay attention to the individual's culture(s), context(s), experiences, and how they make and/or negotiate their identities and meanings of the self.

Understanding Disability

The way society perceives individuals with disabilities is affected by pre-constructed attitudes—whether social, cultural, etc.—towards disability (McDermott & Varenne, 1995). These attitudes affect the way individuals with disability are treated. While there are many models that define and theorize disability (e.g., Nordic relational model, the minority group model, etc.) the model that dominates the field of disability studies in the global North is the social model of disability. According to the social model, the cause of disability is heavily dependent on the power dynamics and organization of the society that contextualizes it, rather than just on the impairment of the individual (Degener, 2016). As Degener (2016) explains “{d}isability as a social construct is the main feature of the social model of disability” (p. 2).

Mallett and Runswick-Cole (2014) state, disability studies has been chastised for failing to incorporate perceptions from the global South. They add, disability concerns impacting the global South are either ignored or only sporadically addressed in mainstream disability studies. The primacy of the social model in disability studies analyses is problematic, because it was developed by educated academics who are white and belong to middle-class; thus, it can only provide a restricted understanding of disability in the global South.

Intersectionality

Intersectionality is a term coined by Kimberlé Crenshaw (2017) to describe the numerous social dynamics, social identities, and ideological instruments through which power and disadvantage are represented and justified. Intersectionality—a critical theory foundation, as Goethals, et al. (2015) explain—is an analytic framework that attempts to capture the multiple positionalities of individuals by emphasizing differences among social groups. It aims to shed light on the multiple interacting elements that have an impact on people's lives and to determine how these various systemic circumstances, which change in place, time, and condition, work together to replicate inequalities. It goes beyond the conventional frameworks that divide social life into discrete or pure streams. It asserts, people have numerous roles and identities, and as members of more than one group they might experience both privilege and oppression at the same time. Thus, evaluating "disability" at the intersection of other categories, power dynamics become

more visible, and it becomes clear that no one social category is more essential than the others. Intersectionality pushes the researcher to view the various categories humans belong to “as mutually constituting processes” (p.78). Intersectionality seeks to comprehend “unique experiences and perspectives at the intersection of two or more social or cultural categories and positions that intertwine as complex, overlapping, interacting, and often contradicting systems” (p. 78) rather than simply adding categories to each other. Lastly, intersectionality is used to analyze the ways in which power and power relations are sustained and reproduced. Thus, centering the voices of “unmarked and unheard groups” (p.78) becomes essential.

Literature Review

Review Method and Analysis

I conducted a thematic review not only to have a good grasp and understanding of the literature targeting disability, religion, ethnicity, and gender in the Arab world, but also to describe how they influence each other. The scope of the reviewed literature was on disability in Islamic or Arab contexts. In my search I applied no restriction on publication date (the search was conducted in March 2021), nor on the types of articles, the methods, or theories used. The works I reviewed included empirical studies, book reviews, literary autobiography, analyses of literary works, and other reviews of literature. I utilized an analytic approach similar to Interpretative Phenomenological Analysis (IPA). Accordingly, I followed and modified Pietkiewicz and Smith’s (2014) guidelines. Thus, as a first step I read and familiarized myself with the targeted literature. I curated paragraphs that explored the intersectionality of disability (identity and experiences) and religion, ethnicity, and gender in the Arab world. I curated quotes that I considered as “gems,” as explained by Eatough and Smith (2017), and I took detailed notes of my reflections and observations. During the second stage, all documents were uploaded to Dedoose. I created an initial set of codes that were informed by my notes and reflected main ideas from the readings. I then reread the documents, coded the texts, and further refined my codes. During the third and final stage, I synthesized connections between the themes, and grouped them “according to conceptual similarities, and provid{ed} each cluster with a descriptive label” (Pietkiewicz & Smith, 2014, p. 12).

Summary of Themes

From the reviewed literature I formulated the following themes and *subthemes* that unpack a complex intersectionality²:

1) Ability and disability: signs of favor and disfavor in God's eyes

a) *Disability, Deviance, and Otherness: Worship is the Connecting Thread*

b) *God is 'Perfect': An Extension of Ableist Ideology*

c) *Being Able-bodied is a Gift from God*

2) If God is 'perfect,' why would he create 'imperfection,' 'illnesses,' and 'pain'

a) *God Inflicts Illness and Disability to Punish those who Sin*

b) *God Inflicts Illness and Disability to Test His Followers' Faith*

3) Disability is not just a metaphoric representation in Islamic texts (e.g., Zahra (2018) argues, the use of "deaf, dumb, and blind" in the Quran is purely metaphorical. She explains that the Qur'anic use of these terms is only in reference to those who are "metaphorically disabled"—which is different, as she explains, from those who are physically disabled. The "deaf, dumb, and blind", then, is a reference to the non-believers who refuse to see, understand, and hear the Islamic message as 'Truth.' Yet, Abu Jafar (1983) and Kathir' (2003) (influential Muslim scholars and exegetes) Quranic interpretation confirm, the verse that describes the state of the nonbelievers as being "blind, mute, and deaf" on resurrection day is their actual physical state. Thus, in these verses, disability is not used metaphorically.

a) *Other Representations of Disability in Islamic Texts* (e.g., normal part of the human condition (Al-Aoufi, et al., 2012; Bhatta, et al., 2009; Blanks & Smith, 2009), disabled individuals as participating members in both the spiritual and social worlds (Bhatta, et al., 2009; Blanks & Smith, 2009; Miles, 2002; Schuelka, 2013). In other instances, disabled individuals are portrayed as "dumb" and "useless" (Miles, 2002)).

4) Disability, stigma, and shame

² Themes will be further discussed during presentation

a) *Intersectionality of Arab Culture and Islamic Teachings: Reinforcement of Stigma*

5) A vicious cycle of alienation (e.g.: families often hide their disabled children (Nahal, et al., 2017; Turmusani,1999) and deny them any opportunity to acquire services (Turmusani,1999). Families of disabled daughters are more likely to hide and deny having a disabled daughter, as they fear it would reduce other members' chances of getting married (Turmusani,1999)).

6) Disability further 'marginalizes' and 'stigmatizes' an already 'marginalized' and 'stigmatized' female identity

a) *A Vicious Cycle of Inferiority: Not Worthy*

b) *Abuse and Neglect*

c) *Disabled Women 'Bring' Shame and Stigma not Only Upon Themselves but Upon Their Families: A Form of 'Social Deviance'*

d) *"Disembodied" Existence: Silenced and Absented*

e) *The Unmarriageable*

7) Disabled or not, he is still a man

a) *Still Marriageable, Protectors, and Providers*

b) *Still Worthy of Education, Employment, and Services*

Discussion

Under the Islamic tradition, disability definition is connected to one's ability to perform their religious obligations. Such understanding led disability to be part of a bigger category, rather than a separate and independent category. Overall, disability in Islamic texts is often incorporated under concepts of misfortune and calamities. Thus, disability became something that needs to be prevented and 'healed.' Since human life is understood in its relationship with its creator, then the image and essence of God becomes essential to how Muslims understand their existence. Muslims believe that God is omniscient, all powerful, just, merciful, and most importantly represents 'absolute perfection.' With His mercy, God blesses mankind with gifts: health, 'beautifully' formed bodies, and senses. Such understandings led many prophets and

Muslim scholars to contemplate the existence of disability and illness. They rendered disability and illness as either a punishment for the individual, their family, and/or society as whole, or as a test of one's faith.

Interestingly, gender was never discussed in any of the Islamic text that I have analyzed for this project. One can argue that the Arabic language is masculine and when the word "man" is mentioned in the Qur'an, it references both men and women. That argument might hold true when the Qur'anic verse speaks of general rules, as was observed under the first theme (the word "man" meant all humans). Yet, when the text speaks of specific incidents, almost all (from Hadith and the Qur'an) were about disabled males. Especially when the event spoke of participating in the social world (Ghaly, 2009; Ghaly, 2016).

Disabled females were only mentioned in one Hadith—that is from the literature reviewed in this project—cited by Miles (2002). This involves a story of a woman who had epilepsy and experienced seizures during which her body becomes uncovered. She went to prophet Mohammed asking him to pray that God would heal her. Mohammed replied, if she is patient with her illness, she will enter Paradise. The woman chose to be patient but asked the prophet to ask God to not let her body uncover during seizures, which he did. While the story confirms previous understandings that disability, in this case, is a test from God, it also becomes an opportunity to convey religious perception of the female body; a female body must be covered. Further, the woman's name is never revealed, unlike other stories and Hadiths about disabled men who are often named and glorified.

The intersectionality of disability and religion is further complicated when interwoven with ethnicity and gender, as they intensify the layers of oppression faced by disabled people in the Muslim Arab world. The amount of stigma and shame in Arab societies inevitably creates a vicious cycle of alienation to both disabled individuals and their families. As previously discussed, not only did Islamic text leave Arab societies' negative perception of disabilities unchallenged, but it also further reinforced paternalistic and charitable attitudes towards disabled individuals. It transformed their bodies to an opportunity for seeking God's redemption. Such Islamic representation of disabilities, coupled with tribal traditions and perception of honor and shame in Arab societies—especially in traditional ones, created an environment in which disabled individuals are often shamed, ostracized, and discriminated against.

It is often assumed that disabled Muslim Arab men and women experiences are similar. This review explored the faultiness of such assumptions. Gender adds another layer of more intensified oppression endured by disabled women, as distinct from disabled men. Although these gender-related issues explored are in many cases like issues experienced by both able-bodied and disabled women, disability in this context increases the perceived inferiority and vulnerability of women. Further, it reinforces their subservient position in their society. To say the least, gender power dynamics strongly influence disability experiences in the Muslim Arab world.

Conclusion

I began this paper by stating the faulty assumption that disability experience is homogeneous. The diversity in disability experience in the Arab Muslim world specifically, calls for an intersectional approach that takes religion, ethnicity, and gender seriously. Intersectionality recognizes that individuals can belong to multiple disadvantaged groups, which can create multiple systems of disadvantage (Bešić, et al, 2018). To analyze these systems of disadvantages, it is necessary to look at the intersectionality of the different categories individuals claim and belong to.

This review focused on scholars' understanding and perception of disabilities. It demonstrates the complex ways in which the intersectionality of religion, ethnicity, and gender are essential in understanding the experiences of disabled Muslim Arab women and men. In the Arab world, Islam seems to be the most influential force by which Muslims organize and understand their existence. Yet, the lines between Arab culture and Islam are blurred. Imbalance in gender relations is present in Islam and is further exacerbated by the patriarchal ideologies present in the Arab world. Thus, disability understandings and representation are strongly influenced by Islamic teachings and Arab culture and traditions. Further, disability experiences are influenced by the gender power dynamics present in a Muslim Arab world; the female seems to occupy the most disadvantaged position.

Reflecting on identity discourse, disability identity as a concept was not mentioned in any of the reviewed literature. Overall, one's identity "is defined both by common objective elements, such as language, history, religion, customs, institutions, and by the subjective self-identification of people" (Huntington, 1997, p. 43). Thus, it is not surprising to see that identity in the Arab Muslim world is influenced and formed in accordance with the collective ideologies

of said patriarchal society. That is, leaving one's identity to be highly informed by their religion, ethnicity, and tribal affiliations. Gender as an identity is informed by both ethnicity and religion, and one must adhere to gender norms in order not to bring shame to the family/tribe.

Disability in pre-modern Islamic context never stood as a fully independent group, which might have led to diluting it with and attach it to other identities. In the modern Arab Muslim world this reality started to change, especially after the Arab Spring. Still, there is a lack of a political and critical discourse around disability experience and rights. Nonetheless, disability continues to influence one's experience—as it can further stigmatize an already stigmatized female identity—and is also influenced by one's context—which can be observed in the different experiences between disabled men and women in the Arab Muslim world.

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“Handicap Removed”: An Alternative Path to the Social Model

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The title of this paper alludes to voiceover narration in a short film commissioned by Hofstra University, where I teach. In 1963, the Trustees at Hofstra resolved to make the campus accessible to people with physical disabilities, and for the next two decades the University installed ramps, lowered public telephones and water fountains, and retrofitted multistory buildings with exterior wheelchair lifts. Hofstra also commissioned a 1966 film *All Things on Wheels Aren't Equal* to advocate campus accessibility. The film's opening shot presents a key unlocking a wheelchair lift, as the unseen narrator declares, "Handicap removed." By suggesting that an accessible environment eliminates a handicap, this scene anticipates the social model of disability. A few moments later, the narrator again anticipates the social model by asserting, "There are over a million disabled people under the age of twenty-one handicapped by a curb, a flight of stairs, something out of reach." Here, the physical environment rather than the wheelchair user's physical impairment "handicaps" or disables. The final shot of the film presents a young boy in a wheelchair, as the narrator observes, "Occupation, today a child, physically disabled, tomorrow, teacher, artist, scientist, lawyer, architect, handicapped? That's up to us." Once again, the film differentiates between an impairment rooted in physiology and a handicap determined by the social environment, that is, "us." Mike Oliver and Tom Shakespeare have both traced the earliest articulation of the social model of disability to *The Fundamental Principles of Disability* published by the British Union of the Physically Impaired against Segregation (UPIAS) in 1976 and based (the pamphlet's title page asserts) on a discussion held in November 1975 (Oliver 2004, 19, Shakespeare 2014, 12). There UPIAS asserts, "it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society" (3). In this paper, to understand the intimation of such concepts in the Hofstra film produced nine years earlier, I identify an alternative source of the social model and reassess a disability-studies critique of the twentieth-century rehabilitation movement.

The path to that alternative source passes through the career of Harold Yuker, the psychologist who developed and published the *Attitudes Toward Disabled Persons* (ATDP)

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scale in 1960 and helped lead Hofstra's Program for the Higher Education of the Disabled (PHED). Although the film credits identify Harold Goldberg, Yucker's colleague in the Hofstra Psychology Department as screenwriter, they identify Yucker as "Hofstra Project Director." Writing ten years after UPIAS published *The Fundamental Principles*, Yucker distinguishes between disability ("a person's physical or mental condition") and handicap ("the way a person is treated;" Yucker 1986, 36). For a source of this distinction, Yucker cites not the UPIAS manifesto but rather the 1953 second edition of *The Rehabilitation of the Physically Handicapped* by the pioneering rehabilitation physician Henry. H. Kessler. Tom Shakespeare identifies "forerunners of the social-contextual approach" in America as early as 1958 (2014, 19). The articulation of such an approach in Kessler's writing, though, necessitates both pushing that historical horizon back to 1935 and reassessing Ruth O'Brien's critique of Kessler's advocacy for rehabilitation medicine.

"[T]here have developed," Kessler writes, "social attitudes and legal limitations which seriously handicap the . . . disabled in their efforts to earn a livelihood" (1935, 3). This statement unequivocally asserts, to use more contemporary diction, that the social and legal environment disables, that is, causes physical (and perhaps mental) impairments to function as disabilities. It could fit comfortably into a document of the 1970s disability-rights movement such as Frank G. Bowe's landmark *Handicapping America* (1978). Kessler, though, wrote that statement decades earlier in a 1935 book with the decidedly dated title *The Crippled and the Disabled*. Writing a dozen years later in *Rehabilitation of the Physically Handicapped*, he self-consciously proposes a "social and economic" definition of disability rather than a "medical" one. "The presence of a physical defect, however, does not constitute a disability," he writes. "Only when the defect causes an actual restriction of activity or arouses a psychosocial prejudice, will it be so defined" (1947, 12-13). In mid-century America, such psychosocial prejudice even causes stigmatized somatic traits that do not constitute functional defects—"race or color," for example—to function as "social handicaps" (1947, 18). The person living with a functional impairment, Kessler contends, "bears a double burden, his actual disability and the social restrictions it incurs" (1947, 19).

Kessler's understanding of other, earlier models of disability prepared him to formulate a nascent social model. He devotes nineteen pages in his 1935 text to a historical survey of social attitudes toward people with disabilities. He recognizes what disability scholars have termed a religious or symbolic model in which people with disabilities are "appraised morally"

(1935, vii), especially in medieval and Reformation Christianity. Impairments were interpreted as “the result of evil action,” he writes, and “It was assumed that the crippled in body were crippled in mind as well” (1935, 18, 19). He notes the rise in the eighteenth century of what we might term a “charity model” making people with disabilities dependent upon “the pity and the mercy” of the community and focused primarily on confining them out of sight (1935, 21). According to Kessler, the rise of orthopedics displaces the religious model and inaugurates a new (medical) paradigm: “The power to improve the defective physically, the insistence upon change and remolding rather than the former submission to the inevitable or the pious acceptance of an unfortunate condition, characterize all subsequent endeavor” (1935, 22). As if anticipating a turn to a social model, Kessler credits orthopedics with “more efficient means . . . to change the social attitude” (1935, 22). Not surprisingly, then, in that same text he bluntly asserts, “The disabled person is merely a psychosocial concept, which has developed as the result of deeply rooted human prejudices and economic necessity” (1935, 13). Here, the phrase “economic necessity” appears to allude to Kessler’s charge that leaders have cited workers’ disabilities to explain away high unemployment. If, as experts claimed, the U.S. reached full employment (“the peak of manpower utilization”) in 1946 “with an irreducible minimum of two million unemployed (due to age and physical incapacity),” then, he argues, the Depression era estimates of five million unemployables” were “false.” Since “no solution” to a “critical social and economic problem” was “available it was necessary to invoke a scapegoat” (1947, 18).

Those familiar with Kessler through Ruth O’Brien’s critique of rehabilitation medicine in *Crippled Justice: The History of Modern Disability Policy in the Workplace* (2001) may find the account of his thought that I offer here surprising. Far from crediting him with articulating a nascent social model, O’Brien contends that Kessler and other rehabilitation physicians “developed a medical model for the whole of society” (2001, 22). In O’Brien’s account, that model did not focus on better accommodating people with disabilities but rather on preventing such people from impairing society, since, she explains, “an unrehabilitated individual could weaken and erode society’s health” (2001, 28). Psychiatrists who strongly influenced rehabilitation medicine recognized, O’Brien contends, that “Disabled people were also crippled by a society that held them in low esteem. But rather than placing the burden on society, [these] psychiatrists thought the person with a disability should shoulder it” (2001, 50). In sharp contrast, writing in 1935 Kessler insists, “The disabled man must not only be cared for and educated so that he may be able to fill an independent place in the social and economic life of society, but the attitude of the general public—of children, parents, workers, employers--

must be changed, so that the afflicted person will be accepted by them as a natural unit of the common society to which all belong” (1935, 22).

O’Brien also contends that “the rehabilitation movement embraced the norm.” “Rehabilitation doctors,” she asserts, “treated disabled people with the hope that they, too, could fit into the middle of the bell-shaped curve” (2001, 59). Writing in 1935, though, Kessler critiques the concept “normal” and bluntly asserts, “There is no such entity as a normal person” (1935, 4). Kessler addresses three conceptions of normality as either a) ideal perfection, b) absence of defect, or c) a statistical average. To dispute the first two, he cites empirical evidence, including his own seven-year study of over 6500 New Jersey factory workers. He found only 7% of those workers “free from gross defects detectable by physical examinations” (1935, 5). If the ideal or the absence of defect is so rare, can it reasonably be considered “normal”? When he returns to this topic in 1947, draft and discharge statistics provide further evidence. He opens *The Rehabilitation of the Physically Handicapped* with the troubling fact that 40 percent of “selectees for military service were rejected because they could not meet the standard physical requirements” (1947, 3). The high percentage of candidates rejected from military service plus their subsequent success (alongside “women . . . and the superannuated”) as workers in defense factories prompt Kessler to recommend reassessing definitions of physical (and industrial) fitness. Under “false concepts of physical fitness,” he charges, “Vague standards have been created that have condemned those with physical defects as unproductive and socially useless” (1947, 3-4).

Kessler’s critique of the third, statistical conception of normal is less probing. He asserts that the appearance of “objectivity” is illusory; “social judgments,” rather than mathematical averages, function as “criteria or standards” (1935, 5). Although Kessler omits an illustrative example, one appears in Lennard Davis’s analysis of how the eugenicist Francis Galton sought to avoid the “middling of desired traits” under a bell-shaped curve (1995, 33). To avoid endorsing mediocrity by treating average intelligence or height as “normal,” Galton substituted ranking for averaging, revised the normal curve into quartiles and thus created what Davis terms “a new ideal” for extremes of desired traits. Kessler’s skepticism regarding self-serving conceptions of normal leads to a less sophisticated anticipation of Rosemarie Garland Thomson’s concept of “normate:” “the social figure through which people can represent themselves as definitive human beings.” “The use of the term normal,” he contends, “implies a judgment in which we, who consider ourselves normal, use ourselves as the standard and the subject of our attention as the deviation from that standard” (2017, 5-6).

O'Brien also charges that, inspired in part by Sigmund Freud's reading of the deformed villain Richard III, Kessler's form of rehabilitation medicine attributed "twisted and maladjusted personalities" to people with physical or mental impairments (2001, 7). Kessler does assert that "Personality maladjustment often plays a more important role in the . . . incapacity to work than the physical defect" (1935, 10). That claim, however, leads to another incipient formulation of the social model. "Organic defects have often been over-emphasized An organic disability becomes an actual disability only when the individual senses a defect and feels a consciousness of that defect reflected by his environment" (12). Here again, he asserts that the environment renders the defect a disability.

Further, Kessler condemns dismissing unemployed workers with disabilities as "social misfits." "The dominant factors in this maladjustment," that is, the inability of such workers "to secure or hold jobs," he contends, are not their twisted personalities but rather "national economic conditions and local prejudices" (1947, 18). Far from assuming that "disabled people all suffered from emotional maladjustments," Kessler asserts that "In a great number of soldiers mutilated by war, a defense reaction never develops" (1935, 10; O'Brien 2001, 21). Although Kessler does address the "retraction of the ego" in a minority of such cases, he also employs psychoanalytic terminology to pathologize ableist prejudice. The "inhibited, repressed, and limited ego," he asserts, finds needed "satisfaction" through superiority over the "cripple." "Prejudice" against the "physically handicapped," he contends, "is a poison compounded of demonology and ego need." (1947, 12). He thus attributes ableist prejudice to its own form of personality maladjustment.

Moreover, O'Brien sometimes appears to conflate emotional and vocational maladjustment. Kessler reports that he "considers the disabled as maladjusted vocationally and seeks a remedy" for that maladjustment "in legislation and changing social attitudes" (1935, 10). His emphasis on adjusted social attitudes here conflicts with O'Brien's contention that Kessler's rehabilitation medicine expected people with disabilities to "accommodate society rather than have society accommodate them" (O'Brien 2001, 5). Kessler uses the term "maladjustment" broadly to discuss social dislocation and an absence of fit between individual and society. The opening sentence of Kessler's 1935, Depression-era monograph situates that text in a moment of "serious," international, "economic and political maladjustment" (1935, vii). He welcomes a more enlightened twentieth-century attitude that attributes poverty not to individual moral failings but rather to "economic waste and inefficiency" produced by

inadequate “social planning.” Far from attributing emotional maladjustment to people with disabilities, there Kessler explicitly regrets that such an enlightened attitude, attentive to the impact of social planning and free of moral stigma, has not been “applied to the problems of the person handicapped by a crippling deformity” (1935, vii). For Kessler, maladjustment is often a socio-economic problem rather than an individual one.

I can propose possible explanations for the disparity between my account of Kessler and O’Brien’s. O’Brien focuses her study on the second half of the twentieth century, starting with postwar developments leading to the 1954 Vocational Rehabilitation Act. At times, she appears to attempt to fit Kessler’s career into the scope of her study. She asserts, for example, that Kessler “generated his views about rehabilitation during World War II,” even though he began serving on the New Jersey Rehabilitation Commission in 1920 and had published two monographs on the subject by 1935 (O’Brien 2001, 42; Kessler 1970, vii). O’Brien’s discussion of Kessler rests on a narrow foundation: she directly cites just one of Kessler’s books, *The Principles and Practices of Rehabilitation* (1950), a somewhat unrepresentative text. Published nineteen years after Kessler’s first monograph on rehabilitation, this volume is an edited collection with most of its twenty-one chapters written by others; Kessler’s own contribution is necessarily less developed than in his three earlier monographs.

Kessler’s views remain largely but not completely consistent over forty years of writing about disability. His 1970 monograph *Disability—Determination and Evaluation* echoes passages from earlier volumes and endorses “the dichotomy of concepts between impairment and disability” (1970, viii). Even so, Kessler struggles to incorporate his critique of normality fully into his writing. He appears to embrace the norm, as O’Brien charges, by continuing to differentiate between the “normal” and the “physically handicapped,” even after asserting, ““There is no such entity as a normal person” (1935, 4, 11, 25). In fact, in the 1950 text that O’Brien cites, Kessler casually (and chillingly) discusses surgical normalizing in the case of a boy born with six fingers on one hand and consequently regarded as accident prone by potential employers. “It was, of course, a simple matter,” Kessler writes, “to make him perfectly normal by removing the extra finger” (1950, 36). In one passage, in his 1947 *Rehabilitation of the Physically Handicapped*, that appears to substantiate O’Brien’s critique, Kessler implies that psychosocial prejudice is one more obstacle for the person with disabilities to overcome: “This

truculent attitude on the part of society is the greatest hurdle that the disabled person is called upon to surmount” (1947, 18). Here, though, the passive formulation “is called upon” enables Kessler to cite this expectation without necessarily endorsing it. In fact, two pages later he poses a rhetorical question that challenges the reasonableness of such an expectation: “Of what use then are physical restoration programs, education and vocational training, if the physically handicapped are to meet discrimination and exclusion on every side?” (1947, 20).

Moreover, Kessler’s ideas seem most radical in their Depression era formulation, which falls outside the focus of O’Brien’s study. Kessler situates his 1935 monograph in response to an international economic, social, and political crisis that has, he asserts, “intensified” the problems of people with disabilities. He wonders whether America’s “democratic and capitalistic society” will be able to match the “achievement” of Soviet Russia which appears to have solved “the struggle of the disabled for economic and vocational status” by absorbing them “into the industrial economy” (1935, vii-viii). That 1935 text does not focus on rehabilitation practices, as does the 1950 volume that O’Brien cites; instead, it investigates “what role legislation has played in reducing the social and economic differential between the disabled and the nondisabled” (1935, viii). Writing months before members of the League of the Physically Handicapped conducted a sit-in for more than a week at the New York City Emergency Relief Board to demand their fair share of Works Progress Administration jobs, Kessler adopts the relatively political diction of rights and justice, as he advocates “do[ing] justice to” people with disabilities, “advanc[ing] their claims for recognition,” and affording them their “rightful opportunit[ies]” (Longmore 2003, 54, 65-67, Kessler 1935, vii, 9, 48).

For many reasons, no doubt, Kessler’s call for “organized political and social action,” informed by a recognition that society disables, did not produce a disability rights movement like the one that UPIAS’s *Fundamental Principles of Disability* helped create (1947, 16). O’Brien charges that Kessler and other physicians who conceived of themselves as participants in a “rehabilitation movement” misconstrued “the definition of a social movement.” Instead, these professionals who acted without the “grassroots participation” of disabled people, formed, O’Brien contends, “an epistemic community, one united by a coherent set of ideas, values, and beliefs that influenced policy makers (2001, 29). Kessler’s advocacy does seem to have fallen short of the standard “Nothing about us without us.” Still, the experience of the short-lived League of the Physically Handicapped, a grassroots organization composed of people with disabilities suggests, as one might expect, that other factors delayed the rise of a disability rights

movement. Paul K. Longmore observes that the League, active from 1935 to 1938, “advocated piecemeal gains . . . rather than systematic reconstruction of disability policies and programs, let alone society.” The League’s analysis, Longmore asserts, regarded disability as a “social and political” condition rather than a “medical and moral” one but fell short of probing how disability “as the counterimage of ‘normality’” functioned in managing social and class relations (2003, 83-85). The advocacy that both Kessler and the League undertook demonstrates that a nascent social model was not sufficient to enable the scale of social change that people with disabilities accomplished late in the twentieth century.

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Shattered Birds: An Autistic Response to Sandra McPherson's *The Spaces Between Birds*, Donna Williams' *Nobody Nowhere*, and Anand Prahlad's *The Secret Life of a Black Aspie*

Caitlin Flaws¹

Autism has held a spotlight in our culture, for better and for worse. The rise of the anti-vaccination movement has reached another level of insidiousness within the COVID-19 pandemic. What the anti-vax movement does to the autistic community when people claim that vaccines cause autism, they vilify autism as a tragic and life-ruining developmental disability and thoroughly other those on the autism spectrum. And yet, with autistic icons like Temple Grandin, the public sees autism spectrum disorder as a superpower.

For me, my autism tainted me as odd. Odd in a way that created a cloud of dis-ease around me when anyone realized, oh, she's not like us. I was autistic in the way that I couldn't use my own voice, unless it was to repeat what others said. A child who ran out of crowded stores and into parking lots because hordes of strangers overwhelmed me. A kid who could only wear soft, worn-in clothes because new pieces of clothing felt like fire against my skin. A child that cried when plans changed suddenly because I couldn't handle life's complexities. A kid who didn't brush her hair because the bristles of my hairbrush felt like knives tearing through my scalp.

This paper is meant to reflect the autistic existence and the precarity of autistic voice. I will be using personal anecdotes about my life on the spectrum along with the writings of Sandra McPherson's book of poetry *The Spaces Between Birds*, Donna Williams' memoir *Nobody Nowhere*, and Anand Prahlad's *The Secret Life of a Black Aspie: A Memoir*. These narratives will be contextualized by an analysis of autistic rhetoric.

McPherson's poetry book is centered around raising her daughter, Phoebe, who is on the autism spectrum. In McPherson's *The Spaces Between Birds* there are "twenty-eight years of poems" written by McPherson and her daughter, Phoebe (Preface). The poems detail McPherson's experiences while parenting Phoebe and the progression of Phoebe's diagnoses from "hyperactive to learning-disabled to schizotypal to Asperger's syndrome autistic," as well as poems Phoebe wrote as a child and young adult (McPherson, Preface).

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Williams grew up in Melbourne, Australia, in 1965. Her mother was an abusive alcoholic and her father, absent due to Williams' autism blocking him out of her perception, was bipolar. Donna Williams' *Nobody Nowhere* is organized in chronological vignettes, which provide detailed insights into her autistic adolescence. To explore the intersections of race and disability, I will weave in Anand Prahlad's *The Secret Life of a Black Aspie: A Memoir*. Prahlad provides an important perspective as a black man who was diagnosed with Asperger's syndrome much later in life.

This project is written in fragments, which represent what it's like living on the autism spectrum and showcase the beauty of fragmented forms. I've lived a shattered, or fragmented, existence trying to be normal to assuage others and have lost myself in the process. I've become an echo of myself in my attempts to become palatable and tolerable for the rest of the world. An echo, lost in a cave, forever searching for its end.

Texts penned by those on the autism spectrum, or autism memoirs and narratives, illustrate what clinical psychologists cannot do: understand what it's like to be autistic firsthand. Williams, McPherson, and Prahlad contrast each other through their perspectives: Williams and Prahlad are purely firsthand accounts; McPherson is secondhand, from a parent's point of view. Memoir writing, whether one is neurodiverse or neurotypical, is effective in establishing a discourse that is both separate and a part of the writer. In "The Autobiographical Pact" Philippe Lejeune², claims that an author is but a name on the cover of their book and is separate from the "I" present within the text, this notion is particularly effective in understanding the autistic experience in memoir writing. In "Autistic Autobiographies and More-Than-Human Emotional Geographies," Joyce Davidson and Mick Smith³ detail the importance of writing for autistic individuals "Not only do such texts present insider accounts but the very communicative and social challenges that typify the condition mean that those with ASDs often prefer to interact with others via the written rather than spoken word." Autistic memoirists communicate what they think, feel, and need without the stigma that is placed upon their voice.

² Philippe Lejeune, "Autobiographical Pact," *On Autobiography* (Unknown Publisher. Unknown Publication Date).

³ Joyce Davidson and Mick Smith, "Autistic autobiographies and more-than-human emotional geographies," *Environment and Planning D: Society and Space* 27 (2009): 902.

Phoebe has thirteen poems in *The Spaces Between Birds*, and they are all intertwined with her mother's poems about parenting. Phoebe's voice is a defining role within *Spaces*, as it expresses what McPherson cannot about her daughter: her own unique thoughts. In the "Child" section of *Spaces*, the poem by McPherson "Butterflies by a Lake" resides, with the opening lines,

I am told she speaks strangely

And should seek help.

To the psychologist I bring

This mud lit with butterflies (Lines 1-4, 16).

"Mud lit with butterflies" refers to Phoebe and demonstrates the tenderness and love McPherson has for her child, who might be deemed abnormal or atypical to the rest of the world from her diagnoses (Line 4, 16). Phoebe is nameless but is an occupying subject of "Butterflies by a Lake," especially so with three of Phoebe's poems inhabiting the previous pages. Transitioning from Phoebe's words, with lines like, "'I hear pineapple' [vibraphone] / 'I hear noodles' [yodeling]" and "My face looks like jellyfish / My forehead looks like lights in the sky / My forehead looks like snails," to McPherson's loving words towards Phoebe in "Butterflies by a Lake" creates a whimsical tension between the two voices (Lines 1-2, 13 and Lines 1-3, 14). Phoebe's poems in *Spaces* do not have titles, which create an imbalanced dynamic between Phoebe's and McPherson's words. And yet, a single line of Phoebe's words will reside on an entire page, such as, "'This place is full of dogs and full of dumb meaning'" (18).

The tension between mature poetess mother and whimsical weird daughter forces Phoebe's voice to be in flux: her words are strategically spliced between her mother's pages of poetry. Phoebe takes the place of muse for McPherson, whether it be to channel her anxieties about Phoebe's diagnoses or to celebrate her daughter's growth. Phoebe's entries take up an important amount of space, and function as an uplifting perspective between McPherson's lamentations. In an untitled entry, Phoebe writes, "Mamas talk civilized / talk like chipmunks / bears," wherein the childlike idolization of her mother is present, and a fixation on speech in using the word "talk" (Line 1-3, page 19). The preoccupation with Phoebe's speech and demeanor inhabits the rest of the poems with the underlying characterization of Phoebe's autism. Although the space Phoebe inhabits is crucial to countering McPherson's voice, Phoebe's own voice is overshadowed by her diagnoses, which become characters themselves.

In “Butterflies by a Lake” McPherson refers to Phoebe’s echolalia in the lines,

“She said this ... and this...

Orange sayings, midway

From blood to the sun,

One opening then another,

Elegant echolalia –

And the softness of her speech,

Confusing pronouns...” (Lines 5-10, 16).

McPherson emphasizes Phoebe’s speech and language development, which deafens Phoebe’s voice in her following entries. In the single-lined entry a couple pages after “Butterflies by a Lake” Phoebe writes ““This place is full of dogs and full of dumb meaning”” (18). The repetition of “full of,” symbolizes the echo of echolalia, which centralizes Phoebe’s diagnosis. The underlying character of echolalia, in addition to autism, eclipses and taints Phoebe’s voice, and shifts the mood of Phoebe’s entries from quirkiness to uneasiness. When McPherson writes, “Elegant echolalia – / And the softness of her speech, / Confusing pronouns,” Phoebe’s autism is characterized as delicate, manageable, but off-kilter enough to become worrisome to the reader (Lines 8-10, 16). The unconscious characterization of Phoebe’s diagnoses thoroughly others Phoebe and morphs her voice in the following pages. With this uneasy presence of Phoebe’s autism, there is an inherent utilization of autistic rhetoric present in *The Spaces Between Birds*.

Donna Williams was also echolalic, until the age of four. Her father would call her “Polly the possum” or “Miss Polly” as she would “[repeat] meaninglessly [and] echo everything,” she heard others say, like a parrot (Williams, 14). When Williams’ mother would prompt her with, “What do you think you’re doing?” Williams analyzed the exchange as a primal defense mechanism: “Knowing I must respond in order to get rid of this annoyance, I would compromise, repeating ‘What do you think you’re doing?’ addressed to no-one in particular” (12). Like Phoebe, and Donna, I, too, spoke in tongues. At first my family thought I was smart, then they realized I was speaking in quotes from the movie *The Brave Little Toaster*. They noticed I had a hard time talking to other kids, and my preschool teacher observed my self-

isolation where I would play with Barbies by myself or wait for the swing set to empty of kids. I also spoke later than usual, around four years old, exactly like Anand Prahlad. Once I grew out of my echolalic phase of speech, the only people I spoke to were my family members. Loneliness was key to my comfort.

For Williams, her loneliness was defined by outsiders. “People were forever saying I had no friends,” she writes. “In fact, my world was full of them. They were far more magical, reliable, predictable, and real than other children, *and* they came with guarantees” (Williams, 16). Williams, as a child, would see ‘wisps’ which were tiny creatures that provided her whimsical comfort (16). She also saw microscopic pieces of dust floating gently in the air around her bed, and to her they were ‘stars.’ These stars would lend her protection when she fell asleep, even though they were only detectable to her because of her hypersensitive eyesight (17). She may have been alone to others, but for her reality, Williams was surrounded by friendly fantastical beings she would stare at while the world went on without her. Anand Prahlad too was protected by the spirits in his Granny’s house which was on the very plantation where his family were enslaved generations earlier,

I learned the footsteps of spirits, their pulses, their heat. How they come and go between dimensions. How to be possessed by them. How to feel their joy and sorrow. How they travel through light. I learned by watching them walk to and from in dispossessed dimensions. (26)

I do not want to discount Prahlad’s sensing of other-worldly spirits, as he goes on to discuss in his memoir how his detection of spirits is a gift from his maternal grandmother. And yet, this sensation of ghosts can be interpreted as a form of hypersensitivity, just not the kind that many autistic individuals encounter.

In “Children” McPherson writes of the ways in which motherhood, and parenting an autistic child, is consuming, and exhausting,

...to climb aboard me toe for toe, palm

lidding palm so I can’t withdraw

or go out of our single mind

to have another child. (Line 21-24, 20)

Phoebe is metaphorically suffocating McPherson, both physically with the lack of personal space and mentally in the lines, “so I can’t withdraw / or go out of our single mind,” (Lines 22-24, 20). Phoebe and her diagnoses occupy McPherson’s mind so heavily that there is no consideration “to have another child” (Line 24, 20). Strikingly, the autistic rhetoric present in *Spaces* spans the liminal space between love and frustration, affection and fear, and hope and hopelessness towards Phoebe, and her future.

Furthermore, the dichotomy within the autistic rhetoric in *Spaces* complicates the ways in which Phoebe’s and McPherson’s voices interact in their respective poems. McPherson does not exploit Phoebe’s autism, or other diagnoses, but forces them to be acknowledged by the reader. This puts the reader in the precarious position of either falling into the trap of autistic rhetoric or embracing Phoebe’s neurodiversity. Although Phoebe’s voice in her entries is stained with her diagnoses, her subjectivity is not being subjugated, but rather her thoughts are given the space they deserve. Ultimately, it is up to the reader to decide how they will interpret this space: either through exploitation or through inclusion.

Williams was always told she was mad, by her mother, her brother, her peers. But it was her primary school teacher, Mr. Reynolds. The Australian school system of the 1970s often failed to look out for Williams’s disability. She writes, “This teacher spent a lot of time with me, trying to understand how I felt and why I did the things I did...He never seemed to betray my trust” (Williams, 48). Mr. Reynolds was gentle with Williams’ and even invited her to his wedding. But it was her last day of school when,

a friend and I were hanging about in the classroom whilst the other children were outside playing. We looked in the teacher’s book which was left sitting on his desk... I looked up my name under W, and a sentence jumped out at me from the page: ‘Donna Williams is a disturbed child.’ (Williams 50)

Although the comment came from Psych and Guidance, Williams left that school resenting Mr. Reynolds, but also concerned about the person she became as she let down her walls and allowed herself to be vulnerable with another adult. For Williams, other people were her enemy until proven otherwise. She would face endless taunts from her peers, and teachers would either fear her or chastise her for her behavior. For once, an adult recognized her humanity and lent her the patience she so needed. And yet, there was an immense sense of betrayal for Williams when hearing from someone she trusted that she was mad.

For Prahlad, who was diagnosed much later in life, in his 50s, in order to save his relationship with his wife. Even so, his diagnosis,

... and the books took away the two main things that helped me to function. They took away the hope that the ship would be coming, and they took away the pride I felt for being one of the few sane ones. Some of the things I read made me feel even more like a creature than I already did. Some of the words were so cod and clinical. The books described creatures that looked human but were something else. (Prahlad, 4)

Prahlad's words remind me of Alison Kafer's ⁴ groundbreaking work *Feminist, Queer, Crip* where she states that "[if] disability is conceptualized as a terrible unending tragedy, then any future that includes disability can only be a future to avoid." Relating this notion of "unending tragedy" to an autism diagnosis further constitutes the fear we have about people being different.

Autism and its representations have always been inherently fraught. In Malcom Matthew's ⁵article "Why Sheldon Cooper Can't be Black" he states "[autism representation] has tended to adhere to predictable generic patterns that function to re-insinuate ethnic whiteness as metonymic of a masculinized, techno-centric intellect." Even the act of diagnosing and testing for autism used to be classed, and ultimately categorized as implicitly white, as autism researcher Carrie Arnold⁶ observed that, "In 1940s America, those parents [seeking a specialist for their children] were almost exclusively white, and ever since, autism has been treated largely as a white disease." Ethnic whiteness, a term Matthew employs, is meant to function as a homogenizing tool, which in turn hierarchically values the type of autism being represented. Anand Prahlad's words exemplify being black and autistic:

I'll try to describe having Asperger's and being black to you, as best I can, by telling you stories about my life. Being black and coming from the South are no small things. Nor is being older. Most people think of children when they think of autism...They think of white, middle-class parents in suburbs or cities who can help their children. Most people have those pictures of autism because those are the ones on television, in magazines, and other places where there are books and articles. (Prahlad 7)

⁴ Alison Kafer, *Feminist, Queer, Crip*, (Indiana University Press, 2013), 2.

⁵ Malcom Matthew, "Why Sheldon Cooper Can't Be Black: The Visual Rhetoric of Autism and Ethnicity," *Journal of Literary & Cultural Disability Studies* 13, no. 1 (2019): 59.

⁶ Ibid, 60.

The exclusion of people of color and non-cisgender males from representations of autism is a part of autistic rhetoric. In characterizing autism as quirky, pithy, white, and male, neurotypical individuals learn to see autism as purely such. The ethnic whiteness of Sheldon Cooper and other popular representations of autism create an image of the autistic person as an augmented being, which in turn acts as a white supremacist tool. Not only are these representations harmful because they only include one type of person, but they also uplift that singular person, who is white and male, into supremacy which further marginalizes and undermines autistic people of color.

Fictional figures like Sheldon Cooper from *The Big Bang Theory* and Newt Scamander in *Fantastic Beasts and Where to Find Them* are clearly coded as autistic further sanitize the image of not only autistic individuals, but also all disabled people. These characters are usually sexless and used as the sarcastic and sardonic punchlines of tasteless jokes, which erase sexuality and queerness within the autism community.

It is bad enough that autism is stretched into the superhuman/freak binary, but to add white supremacist tendencies to autistic representations in visual media is the final nail in the coffin of what an autism diagnosis can do to a person, not including the trauma that can happen without proper resources early on in life. As Kafer⁷ states “a future with disability is a future no one wants, and the figure of the disabled person, especially the disabled fetus or child, becomes the symbol of this undesired future” (3). An autistic future does not exist. The therapies many autistic individuals are subjected to are meant to eradicate what we are born as, and if our behaviors are not erasable, then the autistic future is one that exists within an institution or the private sphere of a home, not in the public sphere. Unless an autistic person sheds their behaviors and any other quirks that define their abnormality, there is no autistic future.

In the poem “Of Birds and Their Metaphors” McPherson writes

Now that she is nineteen,

Her best metaphors are squandered.

But once she said, ‘You’re brushing your hair

⁷ Kafer, 3.

Like a dead bird,' (Lines 1-4, 46).

McPherson concentrates on Phoebe's aging, and her outgrowth of her whimsical nature. Phoebe no longer speaking in lyrical metaphors and similes represents her adapting to neurotypicality and shedding her speech and behavioral issues associated with Asperger's Syndrome. It is ever-present that although McPherson can feel frustrated towards Phoebe, her immense amount of love for her is unwavering. McPherson fully represents the messiness of parenting Phoebe, and the love that blooms throughout raising her.

I so wish I could talk to Phoebe. I do not think that her "best metaphors are squandered" because she is gaining 'normalcy.' I do not think its normalcy. The birds throughout *The Spaces Between Birds* symbolize the loss of Phoebe's quirks or abnormalities and reveal the dichotomy of being of the autism spectrum. What it means to love an autistic child is that unless your child adapts to social norms, you will become a source of resentment. Williams was subjected to abuse from her mother and peers for years, until she could escape. She was never accepted, lent tenderness, or patience for her quirks. You lose yourself in the process, your difference. The "brushing your hair like a dying bird" is gone. And it is disappointing to grow and adapt to no longer feel alone, only to lose the shiny parts, your sacred parts. Prahlad, while thankful to have a diagnosis explain years of "feeling that [he] was from another planet" there is still a disconnect present between him and neurotypicals (3-4). As an adolescent that went through speech and behavioral therapy I grew, learned, and lost the version of my brain that our society cannot handle. Instead of joining my fellow Martians, I became human. The enlightenment I reached when I figured out, I was never the weird one, and realizing that, yes, I was always just one, one whole person, was irrevocably shattering.

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Questioning Normalcy Narratives: Analysing Esme Weijun Wang's *The Collected Schizophrenias* alongside Kay Redfield Jamison's *An Unquiet Mind* and Elyn R. Saks's *The Centre Cannot Hold*

Unnati Singh¹

Introduction

Disability Studies is structured around challenging the processes involved in the construction of identity which are more often than not reductivist in nature and are dominated by socially, culturally, and politically instilled notions of normativity which serve to school the diversifications of human mind and body by forcing them into certain categories and criteria. It problematizes the mainstream portrayal of disability, and seizes control of the narrative from the hegemonic grasp of ableism. Within the framework of disability studies, wherein identity politics plays such a crucial role, the genre of life writing attains significance, for to quote G. Thomas Couser,

[...] disability life narratives can counter the too often moralizing, objectifying, pathologizing, and marginalizing representations of disability in contemporary culture, they offer an important, if not unique, entree for inquiry into one of the fundamental aspects of human diversity. (401).

By the late twentieth century life writings began to gain currency within disability studies. Kay Redfield Jamison's *An Unquiet Mind*, published in 1995, is one of the pioneering works of autobiographical nature to have given a lived account of manic depressive illness (now known as bipolar disorder). Similarly, *The Centre Cannot Hold: My Journey through Madness* by Elyn R Saks, published 2007, is a vivid exploration of the author's first-hand experience with schizophrenia. Joining the canon, Esmé Weijun Wang's 2019 work *The Collected Schizophrenias* is an investigation of her personal interaction with schizoaffective disorder.

The purpose of this paper is to compare these three works in order to delineate how women with serious mental illnesses (SMIs) navigate through life. The objective is to analyse the selected texts in the light of the question of identity formation and its dual interaction with gender and disability. First, it is important to gain a brief understanding of the concept of normalcy, and how it promotes masking. Second, it is essential to trace the common thread that

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runs through all the selected works, that is, the question of involuntary hospitalisation, and denied motherhood, which serve a direct blow to individuality and self-esteem. It is intriguing to speculate how these authors approach these issues which is also complementary to their respective timelines and thus provide a larger sociological import to their narratives.

Unmasking Normalcy

In his essay, *Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century*, Lennard Davis talks about the origin of the concept of norm. He writes,

[...] the constellation of words describing this concept “normal,” “normalcy,” “normality,” “norm,” “average,” “abnormal”—all entered the European languages rather late in human history. The word “normal” as “constituting, conforming to, not deviating or different from, the common type or standard, regular, usual” only enters the English language around 1840. (3)

This idea of the norm, unlike the concept of the ideal, is a specifically human category which functions on the basis of a simultaneous inclusion and exclusion of the population, depending on the cultural, social, and political environment. The norm constructs as well as manipulates itself over time to claim and control the majority of human population while rejecting that which refuses to fit into its schemata.

The idea of normalcy is therefore inherent to the formation of identity, and in turn, to any and all who reside on the so called periphery of the society. For disability studies, it is crucial to question the self-sustaining discourses centred around an artificial edifice of normalcy, to “reverse the hegemony of the normal and to institute alternative ways of thinking about the abnormal.” Works like *The Collected Schizophrenias*, *The Centre Cannot Hold*, and *An Unquiet Mind*, highlight the hegemony of normalcy and how it encourages masking tendencies among those who deviate from the norm. Wang, Saks, and Jamison, are all highly educated women who are well aware of the causes and consequences of their conditions which gives them a rare sensibility; not only can they experience the illness, they are also aware of how it is perceived in the world—psychiatric or otherwise. The constant threat of slipping into a ditch from where they might never emerge is present in the works of all the three authors, and as a result of this fear, there is a staunch will to improve.

Wang writes, “I tell myself that if I must live with a slippery mind, I want to know how to tether it too” (181). As much as these words are hopeful, they are also laced with an anxiety which comes at the realisation of having a “slippery mind.” Similarly, in *The Centre Cannot Hold*, Saks writes,

As I paged through psychology, psychiatry, and law texts, the case histories on the pages often seemed eerily familiar to me—how easily I could have been any one of them. How easily I could have slipped beneath the waves and simply never come back up again. I wondered if there were a role I could play in the lives of people who suffered in a way that I understood only too well. (86)

When Jamison talks about taking lithium in *An Unquiet Mind*, she lists some rules which she sarcastically calls “Rules for the Gracious Acceptance of Lithium into Your Life”; the first rule says, “Clear out the medicine cabinet before guests arrive for dinner or new lovers stay the night” (71-72). These sentences are loaded masking traits, a superpower of the neurodivergent community where we cosplay as “normal” at the expense of our own well-being.

Involuntary Hospitalisation and the Violation of Identity

One of the highly debatable issues in the psychiatric world is that of hospitalisation. Not only does involuntary hospitalisation come with a deep personal trauma, an irreversible violation of one's personhood, it also borders on the highly biased cultural and political standings and are often detrimental to those who are further marginalized owing to their race, ethnicity, gender, sexuality, etc. In *the Centre Cannot Hold*, Saks shares a harrowing experience of her being held down by four-point restraints which leaves her feeling subhuman. She further dwells upon this issue when she writes,

[...] I spoke to one mental health professional then on the Yale faculty. “Wouldn't you agree that being restrained is incredibly degrading?” I asked. “Not to mention painful. And frightening.” The professor looked at me in a knowing way. “You don't really understand,” he said kindly. “These people are different from you and me. It doesn't affect them the way it would affect us.” If only he knew, I thought to myself. (172).

The cold, detached reply resonates the disturbing detachment the society as a whole feels towards madness. Wang talks at lengths about the various aspects of restraints and involuntary hospitalisation, admitting that she herself has once been committed against her will. She describes the estrangement and lack of autonomy that comes with the hospitalisation, and cites

several cases from both perspectives where an involuntary hospitalisation could have made things better (for the family, friends, etc of the admitted individual) or worse (for the individual admitted against their will).

The Question of Motherhood

Right at the crossroads of disability rights and feminist movement, stands the question of motherhood. Rooted in the notorious sciences of eugenics, the banishment of a woman living with SMIs from the realm of motherhood is not uncommon. The socio-political pressure is suffocating. It is simply unacceptable to the society that a schizophrenic woman might want to have an identity separate from the illness. It is not necessary to have one's illness define oneself. It may be a part of one's identity but is that really all that there is to it? Is a woman suffering from SMI or any disability is necessarily going to be a bad mother? As Liz Sayce and Rachel Perkins have put it, "Often women are given little recognition for the fact that they may desire the valued role of 'mother' as compared to the role of 'mental patient.'"(5). This is a direct attack on the identity of a woman. Again, we can clearly witness the self-sustaining cyclical functioning of the norm which creates gender roles (motherhood being constructed as an indispensable part of a woman's identity) while at the same time makes it impossible for certain kinds of woman to ever achieve that end, thus a systemically excluding them from the majority. Wang, Saks, and Jamison make a personal choice in not having children, but they do not fail to question the ableist discourse which in one way or other affects these choices.

Conclusion

These works invite us to re-examine the transactional principles on which our society is constructed, which values a person only on the basis of their "productivity," while at the same time refusing to create a world which values equality and equity. These works call out the politics of exclusion, the inherent infantilization and debility through which the "norm" functions.

Wang's, Saks's, and Jamison's narratives also highlight that it is possible to thrive with SMIs if there is a balanced combination of medication, therapy, willpower, love and support of friends and family, accommodating workplaces, and sensitive colleagues (while difficult to achieve, it is by no means impossible). The predominantly ableist attitude of the society needs to be dismantled, and the definitions of norm, normal, normalcy, and so on are to be critically speculated, questioned, and challenged.

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Gendered Conceptions of Unwellness in Late 19th Century Psychiatric Practice: An Analysis of The Columbus State Hospital's Index of Patients

Amber Kidd¹

Introduction—20th Century Psychology on the Micro-scale:

In our contemporary “age of trauma” there is a greater cultural consciousness surrounding mental health and unwellness. However, this greater awareness, in large part, does not coincide with a greater understanding of the important historical and cultural backgrounds of these psychological theories and methods of treatment. While a complete historical background is not necessary to have a thoughtful and respectful understanding of mental health care, such background knowledge does provide valuable insight into the ways in which these ideas were shaped by the cultural biases of their time. While it can be easy to assume that medical language is precise and free of bias, this is not the case, and the language we use both reflects and co-constructs the biases that we hold. This paper aims, then, to examine the ways in which the language of psychiatric treatment exemplifies and creates a gendered imbalance in theory and treatment, particularly in late 19th century psychological practice.

This time period offers a particularly rich area in which to work, as the late 19th century is a period in which two momentous changes were occurring in the field of psychology. In the late 19th and early 20th century the idea of psychological trauma as it is currently understood begins developing in the academic consciousness, and there is a gradual shift from theories of hysteria and shock into theories of trauma. These theories of trauma eventually become what we now understand as post-traumatic stress disorder (PTSD). Additionally, in this time, the “era of the asylum” was drawing to its close and moving into the private-practice model of psychiatric care we see today. While these periods coincide, neither causes the other. Rather, these two major shifts in the psychological landscape exemplify the significance of this period for the development of psychology as a field.

While this project engages with the macro-trends in psychological history, it does not aim to be a re-telling of the development of theoretical concepts with an eye towards language.

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Rather, this research is an opportunity to examine psychiatric language at an incredibly small scale, focusing on one year in one asylum, even looking at language use in regard to individual patients. By analyzing these primary source documents, it is possible to gain a greater understanding of the ways in which the macro-trends in history and psychology are reflected in daily life for individual patients. While this research is focused on documents that name and describe patients' diagnoses, the goal of the work is *not* to analyze these diagnoses or treatments themselves, but to consider how the documents' language is influenced by historical ideas, known for being influenced by gendered assumptions about mental health through the examination of how the patients are written about and how their own language is conveyed by a second-hand writer.

Background—Developing Trauma:

While trauma is often thought of as a 21st century idea, its history and cultural significance reaches back much further. The term trauma itself has been used for hundreds of years to denote a physical wound, coming from the Greek word for wound,¹ but “the term trauma acquired a more psychological meaning [...] to describe the wounding of the *mind* brought about by sudden, unexpected, emotional shock.”² In these developing theories “the emphasis began to fall on the hysterical shattering of the personality consequent on a situation of extreme terror of fright. [...] The hysterical female epitomized the shattering effects of trauma on the mind.”³ It is this association with hysteria, specifically the hysterical female, that makes the history of trauma so apt for a feminist linguistic analysis.

This history of hysteria, shock, and trauma is a particularly gendered psychological tradition, because each of these afflictions have been considered, to a greater or lesser extent, something that women were more likely to experience. Hysteria is famously thought of as a woman's disease, even though contemporary scholars have suggested that hysteria is a theoretical precursor to the slightly more androgenous theory of shock.⁴ The association of hysteria with women is so significant that even as men were clearly demonstrating the symptoms of hysteria, new language had to be invented in order to discuss these afflictions.

¹ Oxford English Dictionary, “trauma, n.’,” n.d., <https://www.oed.com/view/Entry/205242?redirectedFrom=trauma>.

² Ruth Leys, *Trauma: A Genealogy* (University of Chicago Press, 2000), 3.

³ Leys, *Trauma: A Genealogy*, 3-4.

⁴ Jill Matus, “Historicizing Trauma,” in *Shock, Memory and The Unconscious in Victorian Fiction* (Cambridge University Press, 2009), 20-61.

This obstructive association of hysteria with women continued even as trauma became the more prevalent term and gained both theoretical and cultural significance. Shell shock and trauma from 20th century wars went unacknowledged or actively dismissed because of their association with women. As psychiatric casualties of war increased, “military psychiatrists were forced to acknowledge that the symptoms of shell shock were due to psychological trauma. The emotional stress of prolonged exposure to violence death was sufficient to produce *a neurotic syndrome resembling hysteria in men*.”⁵ As mentioned, this association of trauma with women resulted in poor care as first, soldiers were ignored, and when this was no longer feasible and “combat neurosis could no longer be denied, medical controversy, as in the earlier debate on hysteria, centered upon the moral character of the patient.”⁶ In part, this character attack took the form of claiming those suffering from shell shock were just trouble-making cowards, but this also took the form of insisting that “a normal soldier should glory in war and betray no signs of emotion.”⁷ In taking this traditionalist view, patriarchal gender norms are used to attack men by associating them with women in order to denigrate them.

While it may seem that the gendered differences in regard to trauma and its related theories were left in the 1920’s, these same issues persist in contemporary understandings of trauma, especially in regard to C-PTSD. Complex post-traumatic stress disorder is one of the latest developments in trauma studies which recognizes trauma as a dysregulation of the nervous system which can come about from long periods of repeated exposure to “small” shocks that, individually, one may not recognize as a traumatic occurrence.⁸ This formulation has also faced gender bias, as the critique has become that these occurrences are too insignificant to be trauma. While C-PTSD could be experienced by any gender, the common example is of sexual harassment, which is then dismissed as annoying, but not traumatic. Even scholars studying trauma will argue that “it is hard not to feel that the concept of trauma has become debased currency when it is applied both to truly horrible events and to something as dubious as the long-term harm to [victim of prolonged sexual harassment].”⁹ It is very clear that the gender bias in psychology was certainly not left in the past, and theories of trauma will continue to inherit these biases until they can be properly addressed.

⁵ Judith Herman, *Trauma and Recovery: The Aftermath of Violence from Domestic Abuse to Political Violence* (New York: Basic Books, 1997), 20.

⁶ Herman, *Trauma and Recovery*, 20-21.

⁷ Herman, *Trauma and Recovery*, 21.

⁸ Patricia A. Resick, Candice M. Monson, and Kathleen M. Chard, *Cognitive Processing Therapy for PTSD: A Comprehensive Manual* (New York, NY: The Guilford Press, 2017).

⁹ Leys, 2.

Archival Findings

Education and Moral Character

The patient indexes include an assessment of each patient's degree of education and their habits of life—meaning their moral character. Both male and female patients were assessed in this manner; however there is a noteworthy difference in the manner in which they are labeled. While all patients were qualified as somewhere between “very good” and “bad,” there were far more adjectives used to describe the female patients (“very good,” “good,” “temperate,” “questionable,” “not good,” and “bad”), while men were either “good,” “intemperate,” or “not given” Of note here, before beginning analysis, is the important fact that the descriptors for patients are not institutionally pre-determined—only allowing the writer to select from a number of options. Instead, the staff member performing the intake assessment is allowed to determine what language will be used to describe the patients' character. Clearly, there is an immense disparity between the language used to describe men's character and to describe women's character. Women have three times as many descriptors, and most of these additional descriptors are ways to label the women as less than good. The only additional descriptor that is positive is “very good,” assigned to only one woman.

While there is a chance that every male patient admitted to the asylum in 1893 was only good or intemperate, it seems far more likely that there are more ways for women to be perceived as having a poor moral character. This linguistic disparity is heightened by the use of “intemperate” to describe the men rather than the questionable, not good, or bad used to describe the women. Intemperance doubles as both an assessment of habit for men and a psychological diagnosis. This dual-use means that men are either good or in need of psychiatric help to become good. Meanwhile, women can be in need of psychological treatment *and* be morally bad. For men to not be good means they are in need of help. For women to not be good it means they are bad.

There are many potential reasons that female patients may be assigned more types of moral character than the male patients, and likely, more than one reason at play. The most obvious potential influence is simply that there is a greater cultural attention on women's behavior, resulting in more language that feels appropriate to describe them. In this sense, it is easier to notice that women have habits of life that are considered poor, because there is a far stricter sense of what good habits of life look like. This increased attention will naturally result

in more language to describe women's behavior generally, allowing for more language to describe these female patients. Of course, these same terms *could* be used to describe male patients, but there is likely less attention given to their character, and these terms may unconsciously feel incorrect if they were applied to men. On the other hand, there is also a history of men experiencing psychological distress and not receiving treatment, because their symptoms were dismissed as trouble making. This is most commonly associated with men experiencing trauma after World War I, but the same issue could be in effect in regard to this linguistic occurrence. If this is the case, there is a potential selection bias demonstrated in the male patients. Any men who may be demonstrating morally bad, trouble-making behaviors, may not be receiving mental health care because the very nature of their perceived "badness" would cause a dismissal of any of their psychological unwellness.

Exciting Causes of Disorder

The second noteworthy example of difference between the male patients and female patients in Columbus Hospital can be seen in the documentation of the exciting causes of their disorders. These exciting causes also offer the greatest insight into the lives of patients, though obviously this is still an extremely limited view of a person. They also demonstrate the ways men and women's lives are conceptualized as fundamentally different beyond their psychological conditions. This is because women are clearly associated with the home in their exciting causes while men are associated with work outside of the domestic sphere. As seen in the chart from the Columbus State Hospital 1893 Annual Report, it is evident that twice as many female patients had domestic trouble as their exciting cause (14 women, 7 men), and only men were assigned "over study" or "financial troubles" as their predisposing cause. Additionally, the five cases of anxiety or worry in men are all named as either "business worry" or "business trouble" in the patient index. No cases of women's anxiety or worry were assigned to business or work. The division of labor here is so obvious as to be nearly stereotypical. *Of course* the most common inciting cause of mental illness in women is domestic trouble. Of note, though, are

details in the patient index that add important nuance to this association of women with domesticity.

The first noteworthy point is that while the exciting cause in female patients is never overwork or business anxiety, this is not because all women are without jobs. Even if all women “only” worked in their homes, this is still labor. In addition, many of these women do have jobs outside of making their homes. The patient index notes the occupations of these women, and while 89 were housewives, 62 were employed or students. Much of this labor was domestic labor, but was still considered a job outside of keeping one's home. Why then are these women never driven to mental illness by overwork or anxieties related to business? Most likely, these women were also experiencing overwork and stress, but because women’s labor has consistently been unrecognized and undervalued, the idea that these female patients could have been made

unwell because of their work would never appear to be a possibility.

COLUMBUS STATE HOSPITAL. 19

TABLE X.—OCCUPATION OF THOSE ADMITTED.

Males.		Males.	
	No.		No.
Metal polisher.....	1	Harness maker.....	1
Potter.....	1	Miller.....	1
Farmers.....	59	Cigar maker.....	1
Laborers.....	43	Cook.....	1
Gardener.....	1	Carriage builder.....	1
Brick masons.....	2	Druggist.....	2
Carpenters.....	3	Shoemakers.....	2
Coal miners.....	5	Agents.....	2
Clerks.....	6	Engineers.....	2
Physicians.....	4	Machinists.....	2
Barbers.....	3	Printers.....	2
School teachers.....	4	Tinsmith.....	1
Stone cutter.....	1	Painters.....	5
Merchants.....	2	Blacksmiths.....	2
Bookkeepers.....	2	Student.....	1
Railroad brakemen.....	2	Saloon keepers.....	4
Policeman.....	1	Railroad conductors.....	2
Surveyor.....	1	Railroad watchman.....	1
Minister.....	1	Undertaker.....	1
Rag picker.....	1	Dairyman.....	1
Ship builder.....	1	Editor.....	1
Farrier.....	1	Messenger boy.....	1
Furnace maker.....	1	Fare dealer.....	1
Collector.....	1	Bank cashier.....	1
Butcher.....	1	No occupation.....	14
Confectioner.....	1		
Tailors.....	3	Total.....	207

Females.		Females.	
	No.		No.
Domestics.....	11	Artist.....	1
Farmers' daughters.....	2	Stenographers.....	2
Housekeepers.....	37	Clerk.....	1
Seamstresses.....	2	No occupation.....	14
School girls.....	5		
Music teacher.....	1	Total.....	165
Housewives.....	89		

Image 2: Chart from the Columbus State Hospital 1893 Annual Report showing the occupation of all patients admitted, divided by males and females.

Additionally, domestic work *is* work, but domestic troubles are considered a moral issue while overwork is considered a physical issue. Because of the high number of women institutionalized because of these domestic troubles, female patients make up nearly 65% of the morally-charged exciting incidents even though they are only 45% of the total patients who entered the facility in 1893. Recall, then, the way in which female patients also face a greater degree of scrutiny in their morality as evidenced by the six descriptors of their habits of life compared to the two descriptors of male habits of life.

With these two seemingly small matters of language considered in light of the other, it becomes increasingly apparent the ways in which women were subtly and implicitly treated as if their unwellness was due to their own moral failure, whereas men did not seem to face this same perception.

A Woman on Fire

The final major point of interest is the death of a female patient discussed in the Columbus State Hospital 1893 Annual Report who died after accidentally catching fire and sustaining severe burns. The language in this report offers insight into the way in which subtle differences in language demonstrate a radically different message and representation of patients. Further, it represents a different rhetorical situation as this document is directed towards an external audience. When first broaching this issue of this accidental death, the superintendent of the asylum writes:

A very unexpected accident occurred in the female infirmary ward, unexpected because of the location and the character of the case in which it occurred. A chronic, demented female patient, who was ordinarily very quiet and dull, succeeded by climbing on the bath tub, in igniting the skirt of her dress from a gasjet, the skirt being thrown over her head. She then ran down the hall and though followed as rapidly as possible by the attendants who were in the hall at the time, the blaze was so fanned by the movement as to cause a fatal burning of the limbs and body.¹⁰

In this telling of the story, the blame for the death is subtly shifted away from the institution, by shifting it towards the deceased patient. This “very unexpected accident” could not have been anticipated or prevented by the employees of the asylum because this “ordinarily very quiet and dull” woman surprised them by her actions. While an accident, the superintendent writes that the woman “succeeded” in her action which implies intention in the woman’s actions. She is made agentive in her tragic death. Even as the attendants tried to help her “as rapidly as possible,” the blame is shifted towards the patient since it is her own running that fed the fire. This analysis is not meant to suggest that the superintendent of Columbus State Hospital is being malicious as he writes about this woman. Rather, this is to point out the way in which this woman is subtly blamed for her death as an unintended expense of shifting blame away from the asylum.

Alternately, this incident is described quite differently only a few pages later by the same writer. In this case he is talking about the need for funding from the state in order to repair the gas system in the building, and he mentions this incident as a consequence of the current, hazardous system. He writes that, “there is also a very considerable element of danger in the

¹⁰ Fifty-Fifth Annual Report of the Board of Trustees and Officers of the Columbus Asylum for the Insane to the Governor of the State of Ohio for the Fiscal Year Ending November 15, 1893 (Norwalk, OH: The Laning Printing Co. State Printers, 1893), 10.

use of gas in the wards, that unfortunately was sadly exemplified this year in the fatal burning of a poor demented patient who was supposed to be the last one liable to such an accident.”¹¹ Compared to the earlier discussion of the patient’s death, she is granted significantly less agency. Suddenly, she is the last patient who should be “liable to such an accident,” and only the gas system in the building is to blame. Again, in analyzing this incident, the goal is not to blame the hospital, but rather to consider the inconsistent ways that agency is or is not granted to patients in order to compliment the message that is being shared. When it suits the institution, this woman is blamed for her accidental burning death.

Given the earlier discussion of the greater scrutiny that female patients’ morality seems to face, the example of this woman offers insight into this dilemma. We see, yet again, the way in which female patients face a subtle but persistent blame for their unwellness. In this rather extreme example, the woman is implicated in her death, but over and over, it is suggested that women are responsible for the situations in which they find themselves. Women’s habits of life are assessed as some variation of not good more frequently than their male counterparts, and the exciting causes of their mental illnesses are determined to be moral more often as well. While there are many things to learn from the patients indexes and the supplementary materials surrounding the asylum, one of the more salient messages is this persistent, implicit blame and moral condemnation facing female patients.

Conclusion

In studying the Columbus State Hospital patient indexes and the asylum’s materials from the same period, the different language used to describe male and female patients is abundantly clear, but more importantly, the implications of these differences are fairly apparent as well. One of the more troubling trends is the blame implicitly placed on female patients and their moral character in assessing and describing their circumstances, from cases of acute melancholia to incidents of women burning to death under the asylum’s care. Given the brief background on psychological theories of the period with a consideration of how they impact the contemporary moment, this gender-bias should not be particularly shocking. The macro-trends in psychological theories as well as their corresponding insidiously patriarchal response have been well established. In examining the records, the goal is not to rehash this history, but to consider how the trends impacted individual patients in their everyday life. It is deeply

¹¹ Fifty-Fifth Annual Report, 13.

troubling to consider the judgments that these women faced—in addition to the already significant stigma of receiving psychiatric care—and it is the goal of the project to lean into this troubled feeling. The macro-trends are concerning, but knowing that a woman in 1893 had written in her patient ledger that her mental illness was precipitated by the “moral effect” of her syphilis creates a much more tangible sense of what women experienced in seeking mental health care.

However, being troubled by the gender-bias evidenced by the language used 19th century patient indexes is not enough. Instead, it is necessary to actively consider the ways in which gender bias has been perpetuated for hundreds of years and remains prevalent today. It is far more palatable to think that psychological theories and medicine are only growing better over time, but it is clear in the development of trauma as a theory—one of the most culturally significant psychological theories of the contemporary moment—that bias is inherited by each subsequent theory unless actively deconstructed. The women of Columbus State Hospital were not any more immoral than the men, nor were the mentally ill any less moral than their neurotypical peers outside of asylum walls, just as the shell shocked soldiers of World War I were not morally bankrupt because they were suffering from the understandable repercussions of trench warfare. By understanding the history of trauma and its patriarchal undercurrent, hopefully it becomes possible to critically engage with these theories in order to begin deconstructing their biases. Such a critical engagement opens up the possibility of deconstructing not just the ways in which the mentally ill are treated differently because of their gender, but it becomes possible, and necessary, to consider the history of associating the unwell with women, as if being woman is inherently denigrating.

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“I am no longer a man”:

Male Sexual Dysfunction as a Disability in Contemporary Arabic Fiction

Muhammed F. Salem¹

Connell defines masculinity as a “pattern or configuration of social practices linked to the position of men in the gender order.”² It is a broad term that encompasses various behaviors, attributes, and rights that place men in a certain rank within a society. In case of lacking either the physical or sexual strength, male privilege within patriarchal societies might be at stake. In line with this, this paper examines male sexual dysfunction within conjugal relations in *You’re Everything to Me (Abo Sayyid)* by Egyptian novelist Yusuf Idris and *Awaiting the Arrival of Manhood (Fī ĩntzārMajī’ al-Rejūlah)* by Saudi novelist and psychiatrist Ibrahim al-Khodeir. Being a socially-constructed stigma in most of MENA countries, male sexual impotence is problematized in both plots as a severely permanent disability. Before discussing both novels, I will further elaborate on key terms, while drawing on the intersections, of hegemonic masculinity and *qiwamah* (male guardianship) in Islam, highlighting how sexual impotence affects both.

The Unerected Hegemon

Hegemonic masculinity denotes continuing practices which justify “men’s dominance over women.”³ Such dominance eliminates any skeptical inquires, with respect to the legitimacy of patriarchy.⁴ Hegemonic masculinity is normative in that it underlies a set of ideal behavior for good men to abide by, while legitimizing, thanks to patriarchal ideology, women’s submissiveness.⁵ This ideology needs to be politically enforced by an upper authority, which provides necessary legal binding for its application.⁶ Far from being inflicted upon women violently, hegemonic masculinity is adopted “through culture, institutions, and persuasion.”⁷ In other words, the “hierarchy” of masculinities effectively operates through benefiting from every

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² Raewyn Connell, “Masculinities: The Field of Knowledge,” in *Configuring Masculinity in Theory and Literary Practice*, ed. Stefan Horlacher (BRILL, 2015), 40.

³ Raewyn Connell and James W. Messerschmidt, “Hegemonic Masculinity: Rethinking the Concept,” *Gender & Society* 19, no. 6 (December 2005): 832.

⁴ Raewyn Connell, *Masculinities* (Berkeley and Los Angeles: University of California Press, 2005), 77.

⁵ Connell, and Messerschmidt. “Hegemonic Masculinity,” 832.

⁶ Connell, *Masculinities*, 77.

⁷ Connell, and Messerschmidt, 832.

possible way of consolidating male superiority. The concept is not stagnant, and it is subject to evolution as it would fit with the current challenges within the patriarchal order.⁸

On masculinity and the potential of hegemony in the Middle East, Inhorn asserts that boys are raised while witnessing the patriarchal model of their fathers; as such, they are enticed to exert control over their sisters and adopt virile attitude.⁹ It is upon marriage that what has been internalized by men surfaces, insofar as they would need to subscribe to the ideal masculine model of the dominant husband.¹⁰ In addition, Muslim societies reinforce hegemonic masculinity, manifested by men's desire in upholding virile behavior in addition to their frequent consultation, and arguably support, of Muslim clerics.¹¹ The latter, embodying the religious authority, socially contribute to the validation of male domination.

In Islam, masculine domination and hierarchy in the conjugal relations stems from the notion of *qiwamah*. Omaima Abou Bakr provides an interpretative discourse analysis where she traces the evolution and the gradual mutation of the meaning of the term. In the Qur'an, *Qiwamah* or guardianship is mentioned in the fourth chapter of *Women or an-Nisa'*:

Men are in charge of women, because Allah hath made the one of them to excel the other, and because they spend of their property (for the support of women). So good women are the obedient, guarding in secret that which Allah hath guarded. As for those from whom ye fear rebellion, admonish them and banish them to beds apart, and scourge them. Then if they obey you, seek not a way against them. Lo! Allah is ever High, Exalted, Great.¹²

According to the Qur'anic verse, men are *qawammun*. At the time of its revelation, the norm was that wives depended on their husbands for financial support. Thus, the "excel" of husbands stems from their status as guarantors of financial security and protection. The rest of the verse deals with rebellious, deviant wives. For the latter, there are various stages for correcting their aberrance, ranging from "admonish[ing]" to "scourg[ing]." The intensity of scourging has been debatable among both Islamic scholars and Qur'an's translators. The original word is *fadribuhunne* or, literally, beat them. Abou Bakr explains that the word has evolved from a

⁸ Ibid, 833.

⁹ Marcia C. Inhorn, *The New Arab Man: Emergent Masculinities, Technologies, and Islam in the Middle East*. Princeton, NJ: Princeton University Press, 2012, 56.

¹⁰ Ibid, 56.

¹¹ Ibid.

¹² *The Qur'an*, 4:34.

mere action to a whole hierarchy.¹³ Since then, Islamic scholars will tirelessly dig too far, adding new connotations to the term.

Arguably, it is more of the misinterpretation and de-contextualization of the *Qur'anic* verse that established *qiwamah* as a hierarchal binary between the man, the breadwinner and source of socio-economic support, and the woman, the devout wife.

Starting from the 1900s, Abou Bakr contends that imams will contribute to the articulation of a conservative gender ideology.¹⁴ For instance, she highlights how Mohamed Abdou's views on men's innate ability for leadership in contrast to women's emotional nature make the former *qawammun* over the latter.¹⁵ Abou Bakr points out the role of some other Islamic figures in perpetuating a conservative discourse on gender such as Sayyid Kutb and Sheikh Metwally al-Sharaawi. Kutb and al-Sharaawi were against the activity of women in the marketplace, being concurrent to her husband who should be the sole leader or dominant.¹⁶

As marriage in Islam only becomes legitimized through consummation, sexual impotence could bereave a man of his *qiwamah* over his wife. Since it is one of the key rights for married women in Islam, women always invoke sharia in their rebuttals.¹⁷ Stiles asserts that in most Islamic courts, "[j]urists from all Sunni madhhabs have contended that impotence or lack of consummation of marriage [serve as] grounds for divorce."¹⁸ In other words, no marriage in Islam would be valid without consummation. Stiles believes that Islamic scholars set satisfaction as a criterion for the legitimacy of marriage, and not reproduction, and as such female sexual pleasure is taken into account.¹⁹

Through three ethnographic cases for women who file for divorce in Zanzibar, Stiles establishes that women use the word "illness" to describe the sexual impotence of their husbands.²⁰ In this sense, male sexual dysfunction is a deviation from the masculine ideal on the base of which men usually take pride in imposing their hegemony.

¹³ Omaila Abou-Bakr, "The interpretive legacy of *qiwamah* as an exegetical construct," in *Men in Charge?: Rethinking Authority in Muslim Legal Tradition*, eds. Mir-Hosseini, Ziba, Mulki Al-Sharmani, and Jana Rumminger (London: Oneworld Publications, 2014), 51.

¹⁴ *Ibid.*, 54.

¹⁵ *Ibid.*

¹⁶ *Ibid.*, 56.

¹⁷ Erin E. Stiles, "Unsuitable Husbands: Allegations of Impotence in Zanzibari Divorce Suits," in *Gendered Lives in the Western Indian Ocean: Islam, Marriage, and Sexuality on the Swahili Coast*, eds. Erin E. Stiles and Thompson, Katrina Daly, (Athens, Ohio University Press, 2015), 247.

¹⁸ *Ibid.*, 248.

¹⁹ *Ibid.*

²⁰ *Ibid.*, 263.

Placing male sexual impotence in the rhetoric of hegemonic masculinity, Potts incorporates the Lacanian reading of the displacement that explains phallocentrism. The phallus, she argues, has been established as synonymic to penis in the symbolic order, effacing its physiological functions of “urination and insemination.”²¹ As a result, male dominance has been defined, and legitimized, by the phallus and sexual potency. Potts asserts that penile erection guarantees that the man would be able to retain his privileged access to power and dominance, and this is how tumescence becomes problematic.²²

Potts draws on how medical patriarchy reduces male sexual functioning into erection.²³ The medical framing of erectile dysfunction construes it as the inability of the man’s mind to control his penis.²⁴ The problem is that phallocentrism establishes the penis as the representation of the man himself, and as such a non-erected penis symbolizes a weak male.²⁵ The following sections delve into the literary portrayal of two Muslim husbands, from different nationalities and social classes, whose sexual dysfunction affect them psychologically while leading them to cast doubt on their affiliation with phallocentrism.

You’re Everything to Me (Abo Sayyid) by Yusuf Idris

In this short story, Idris focuses on Ramadan, the traffic officer, whose life takes a drastic turn as he recognizes that he is no longer sexually functioning. Considered as an intrinsic indicator of masculinity in conjugal relations or more precisely virility, Ramadan’s inability deprives him of self-confidence and leads him to hold that “he is no longer a man.”²⁶ Initially, Ramadan, out of denial, believes that his dysfunction could be a result of a temporal malaise, and that is why he keeps hoping that his relation with his wife, Naima, is intact:

Though a fog veiled the beginning, Ramadan could remember that night clearly. Every minute he had struggled, soaking in streams of sweat, shutting off his mind to the entire world until he and his wife and the bed were all that existed. She pushed him from her again and again, and he damned her to hell over and over, and the struggle went on, halting only when the sleeping boy stirred and resuming when he was heard snoring again, as he drooled down the side of his mouth. He gave up at dawn, and the woman went to sleep, but not he. That night went and other nights

²¹ Annie Potts, “‘The Essence of the Hard On’: Hegemonic Masculinity and the Cultural Construction of ‘Erectile Dysfunction,’” *Men and Masculinities* 3, no. 1 (July 2000): 88-89.

²² *Ibid.*, 90.

²³ *Ibid.*

²⁴ *Ibid.*, 93.

²⁵ *Ibid.*, 94.

²⁶ Yusuf Idris, “You’re Everything to Me,” in *The Essential Yusuf Idris: Masterpieces of the Egyptian Short Story*, ed. Denys Johnson-Davies (Cairo: I. B. Tauris & Company, Limited, 2009), 14.

came and every time he renewed the struggle, fighting desperately for his virility until at last he was forced to give up, saying to himself one morning in a voice he hardly recognized as his own: “There is no might or power but in God.” You’re beaten, man. Finished, washed up.’²⁷

This is an existential crisis for Ramadan which he ought to overcome. Describing Ramadan’s attempts as those of “struggl[ing]”, Idris unfolds the phallocentric mindset of the traditional male husband who needs to re-affirm his virility vis-à-vis his wife. What is symbolic is how Naima’s response, by “push[ing]” Ramadan, leads him to curse and insult her. During sexual intercourse, as per hegemonic masculinity, the man is supposed to be the sole active subject while the female is the passive object. The slightest sign of resistance, or push, constitutes a subversion which jeopardizes men’s domination, feminizing him. In response to her active reaction, Ramadan reestablishes his domination or *qiwamah* by becoming verbally violent.

Acknowledging the limits of his physical strength, Ramadan feels the withering of his masculinity as if his own being, self-esteem, and his survival are subject to his sexual functioning. Henceforth, Ramadan compensates for his incapability with a macho attitude, inside and outside his household. Feeling as if his sexual dysfunction is labeled on his back, Ramadan yields to aggression during his working hours. Inside his home, Ramadan continues mistreating Naima. Knowing that his mother-in-law is aware of his problem, Ramadan not only insults the old lady but also threatens Naima: “By God, you will not sleep under my roof!”²⁸ The English translation does not refer to the exact oath in the original text. This passage asserts how husbands, as *qawammun*, could persistently and manipulatively threaten their wives with divorcing as long as they do not comply with their demands. Deciding to confront her, Ramadan, in total embarrassment, tells Naima the reason of his changed attitude:

‘I . . . I want to do what’s right in the sight of God.’ She looked at him languidly. The shadow of a smile, playing on her face, was about to break at his stumbling speech. ‘I . . . I think it would be better if I divorced you, Naima,’ he blurted out at last. At this she sat up sharply and turned to face him. She beat her breast with her hand and looked at him with eyes full of reproach. ‘Ramadan ! For shame! What is this you’re saying! You are everything to me,’ she exclaimed with indignation, ‘father and brother; the crown upon my head. I am not worth the ground under your feet. I am only your servant, my love. How could you say such a thing! After my hair’s turned gray, and yours too. . . It’s not as if we’re young any more . . . how could you . . .’ A gush of tears stopped the words in her mouth and she couldn’t continue. She unfastened her head-

²⁷ Ibid, 13-14.

²⁸ Ibid, 17.

kerchief and wiped her tears with it as she got up and stumbled downstairs, leaving Ramadan behind, absently passing his fingers over the wrinkles on his face. He smoothed his balding head and passed his hands across his bloated belly. Absently he plucked at the hairs of his leg, most of them turned white, as his eyes strayed to Sayyid, his son.²⁹

Naima's reply awakens Ramadan of his short-sightedness, basing the sustainability of their marriage on her sexual satisfaction. She also reminds him of a greater role he plays. In addition to being a husband, he is a father, and his parenthood surpasses any issues he might have as a husband. Ramadan "pluck[s]" the hair on his leg, which symbolically implies that his masculinity can be transcended to his son Sayyid. Ramadan's faith is also restored through Naima's definition of her role. She re-vows to be his servant, and that he is her master. By bidding mere loyalty and love to him, Ramadan feels that he still dominates Naima, and that she still respects him, no matter whether he is sexually functioning or not. Ironically, Idris depicts Ramadan as feminized in this episode, partly because it is Naima who, in total sagacity and calmness, assures him. Furthermore, Idris's model of the wife is seen to be more rational as she thoroughly evaluates the marriage bond based on all the accomplishments which this bond can offer her, family warmth and children.

Awaiting the Arrival of Manhood (Fī intzārMajī' al-Rejūlah)

Unlike Idris's protagonist, who has been already married for years and whose sexual dysfunction emerged out of aging, the unnamed protagonist here is born with aphallia, and as a result of this congenital malformation he is already aware that he would not be sexually functioning, when it comes to penetration. Moreover, and given that al-Khodeir is trained in psychiatry, the protagonist's lack of sexual desire has to do with the marriages of his voluptuous mother, during his childhood, following her divorce from his father.

Despite that, his colleague, Nadira, admires and tries to attract him so that he would propose to her. Before marrying her, he inquires on whether she might have reserves, would she discover that he has a health problem, alluding to sexual performance. Surprisingly, she timidly assures him that love prevails over anything else.³⁰ After signing *'aqd al-qirān*, the matrimony contract, and even before the day of the ceremony, Nadira attempts to visit him several times, seducing while convincing him that they can consummate their union without

²⁹ Ibid, 20-21.

³⁰ Ibrahim al-Khodeir. *Fī intzārMajī' al-Rejūlah*. Beirut: al-Intshar al-Arabi, 2010, 292, Kindle Edition.

even having to wait for the ceremony. Each time, he pretexts that he would rather wait for after the ceremony.

Spending their first night at a hotel, following the ceremony, Nadira impatiently waits that her husband would have sex with her. He keeps postponing till the other day. Amid her insistence, he eventually decides to let her discover it during their intercourse:

Āmsākatny bīyady w qālt hyā nḡhab īla āl-fīrash nastālki hūnāk fahūnak al-wāḍ‘ akṡhar rāḡa. Rāfktūha. Badā’na al-mūda‘bāt w kont hādhihi al-marā mūstajīban w aḡyānan ādhū al-mūbadāra fī ḡarkāt mū‘yna...bāda’t fī ṡasus jāsadī ilā anna waslāt ilā asfāl batny w akhdhat tabhathū a’ma tūrīd lāknaha a’jāzat ‘an ījad shay’. Hāmsat fī ūdhnī āyn khab’tūh? Antūm al-rījāl a’lykom ḡarakāt aḡyānan tekūn ḡharība jīdān. Lam ājeb a’lá su’alahā. wāsalet al-bāsthū, lam tajīd shay’an. A’tadlāt fī jalsātaha w akatarabet bwajhīhā mīn tīlk al-mantīkah, lam tār shay’an. Ākhdhat tabaḡath ḡhīr mūsadīkā. Ādkhālat yahdaha w haya tanḡūr thum faj’atan wad’at yadūha a’lá famīha ba’d an ātlakat ṡarkhah.³¹

[She took me by the hand and said “let’s go to bed and lie there, it is more comfortable.” I followed her. We started foreplaying and this time I was responsive, sometimes taking the initiative in certain movements. She started feeling my body, until she reached below my stomach and started looking for what she wanted, but she couldn’t find anything. I laughed. She whispered in my ear: Where did you hide it? You men manage to perform the strangest of tricks. I did not answer her question. She continued searching, however, she didn’t find anything. She straightened up and brought her face closer to that area. She didn’t see anything; she kept searching in disbelief. Then, she inserted her hand while looking, and suddenly put her hand over her mouth screaming].

Unlike the domination of Idris’s Ramadan, al-Khodeir’s unnamed protagonist is quasi-feminized in this scene. It is Nadira who arouses him by foreplaying while looking for his organ. Al-Khodeir boldly subverts gender roles in this scene, since the husband is negatively portrayed through his passiveness. By screaming due to the absence of the phallus, Nadira, in oedipal terms, perceives her husband to be as castrated as her. Weeping on its lack, Nadira, as Potts holds, “centralizes sex around penis and universalizes penises, constricting the possibilities of heterosex and limiting what counts as enjoyable male sexual experience.”³² It is as if sexual pleasure is reduced into seeing and touching the erected penis. Telling her that he has been born with no penis, Nadira bawls him out:

Kānet ḡhadībah

³¹ Ibid, 300-301.

³² Potts, “The Essence of the Hard On,” 89.

Taḥdathat bīshakl hūjūmī: idhā kont ta‘rīf a‘nak lāst rājūlan līmadhā tāzawājtany?

Taraja‘t w kūltū lahā: hāl ta‘taberīnī lastū rājūlan?

Kālat: Rājūl? ānt mīthlī...kāyf takūn rājūlan w lays lak ū‘dwan?³³

[She was furious.

She spoke offensively: - If you know that you are not a man, why did you marry me?

I retreated and said to her: Do you consider me not a man?

She said: - A man? You are [exactly] like me... How can you be a man and you don't have a [penis]]?

Nadira’s earlier remark that she would not feel to be married before she would be deflowered highlights how women’s identity, albeit educated—she is a psychiatrist as her husband, is forged by phallocentrism. For her, the absence of her husband's phallus marks his absolute feminization. Moreover, Nadira’s remarks bring Potts’s elaboration of how the phallus is personified in such a way that it symbolizes male strength; its absence automatically signifies the absence of manhood.

From the above narratives, it can be implied that male sexual dysfunction is depicted in Arabic fiction as a handicap, which diminishes men’s dominion as they no longer fulfill the masculine ideal so that they would have the legitimacy to control their wives. The husband in Idris’s story tenaciously tries to conceal his abrupt sexual impotence by resorting to violence, whereas al-Khodeir’s unnamed protagonist has been keeping his secret with the hope that his loving wife would be more considerate of their emotional instead of their physical bond. The role of both wives is noteworthy, for both highlight how hegemonic masculinity inscribes a female code of conduct which the wife should uphold. Idris portrays a loving Naima who, as a middle-aged wife, no longer cares about her sexual pleasure, insofar as her role as a mother subdues any physical need. In contrast, through Nadira, al-Khodeir dramatizes phallocentric ideology, which deems the phallus as an extension to man’s virility. Nadira’s reminder of defloration as a criterion for her passage from virginity to womanhood sheds light on patriarchal injunctions that equally pressure men and women to conform to them.

³³ al-Khodeir, *Fī Intzār*, 429.

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Eugenics, Sexuality, and Disability: Understanding Historical Implications for Intimate Partner Violence

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Introduction

People with disabilities are at an increased risk of violence throughout their lifecycle. From childhood abuse, to intimate partner violence, to caretaker abuse, individuals with disabilities are perceived to be more vulnerable and have reported experiencing violence at rates higher than nondisabled people. Women with disabilities in particular are at an even higher risk of abuse from partners, and this risk only intensifies for women of color, poor women, trans women, and queer women. This paper looks to examine how the eugenics movement furthered assumptions of asexuality and worthiness of the disabled body, perpetuating stigma and creating a framework for violence toward women with disabilities. I will connect the history of the eugenics movement to current assumptions of women with disabilities experiencing violence. I will then connect the foundation of helping professions to the eugenics movement, highlighting the ways in which these professions have continued to perpetuate systems of violence. Throughout this paper, I will emphasize the inherent power dynamics related to gender, disability, and professionalism in an effort to analyze the foundations of helping professions in the context of intimate partner violence today.

The History of the Disabled Body

The view of the disabled body has changed throughout history, relating both to the visual aesthetic of the disabled body and the capitalistic ability to contribute in economic spheres. Early conceptions of disability were often through a religious lens. The religious model was focused on the idea that disability was the manifestation of sin.² In Christianity, the manifestation of sin as disease is prevalent throughout the Bible.³ Disease could then be cured through Christ's love and redemption.⁴ In the Middle Ages, there was a dichotomous view of people with disabilities: some believed disability was an example of God's wrath, forcing

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² Cameron Hunt McNabb, *Medieval Disability Sourcebook* (Punctum Books, 2020).

³ McNabb, *Medieval Disability Sourcebook*.

⁴ Ibid.

families to hide disabled children or kill them.⁵ Others believed that individuals with disabilities were in purgatory and therefore closer to God.⁶ The first asylums, hospitals, and institutions were managed by the Church, further connecting religion and disability.

The medical model of disability evolved from the religious framework. The medical model of disability views disability pathologically, viewing it as an individual deformity or problem needing to be cured.⁷ This framework led to the worth of the disabled body being determined as a person's capability to engage in labor. The religious model also focused on the cure or alleviation of disability, which is foundational to the medical model. In the late sixteenth century, Elizabethan Poor Laws were enacted in order to take care of the "poor and disadvantaged."⁸ This included many people with disabilities, especially those that were deemed unfit or unable to work.⁹ The government's responsibility to care for the poor—especially those unable to work—furthered the assumption that people with disabilities were a burden on society.¹⁰

In the nineteenth-century United States, "ugly laws" were utilized in curating public spaces. In Chicago in 1881, a municipal ordinance prevented individuals who were diseased, maimed, mutilated, or deformed from appearing in public spaces.¹¹ The idea of protecting the public, and especially women, from those with deformities was a driving force of the legislation.¹² The inherent assumption in the ugly laws was that the non-disabled body was the "normal" body.

However, it is important to note that those employed and deemed as contributing to society were at least nominally excluded from these laws.¹³ The ugly laws primarily targeted those deemed "beggars" or taking advantage of the charitable system.¹⁴ Individuals who were

⁵ Michael Rembis, Catherine Kudlick, and Kim Nielsen, *The Oxford Handbook of Disability History* (Oxford University Press, 2018).

⁶ Rembis, Kudlick, and Nielsen, *The Oxford Handbook of Disability*.

⁷ Vannala Hiranandani, "Towards A Critical Theory Of Disability In Social Work," *Critical Social Work* 6, no. 1 (2019): 1-14.

⁸ David Dean, *Law-Making And Society In Late Elizabethan England: The Parliament Of England, 1584–1601* (Cambridge University Press, 2002).

⁹ Dean, *Law-Making*.

¹⁰ Ibid.

¹¹ Adrienne Phelps Coco, "Diseased, Maimed, Mutilated: Categorizations of Disability and an Ugly Law in Late Nineteenth-Century Chicago," *Journal Of Social History* 44, no. 1 (2010): 23-37.

¹² Coco, "Diseased, Maimed, Mutilated."

¹³ Ibid.

¹⁴ Ibid.

unable to find work due to their disability were considered part of the undeserving poor.¹⁵ This is reflective of early capitalism in the United States. Capitalism encourages efficiency, and individuals with disabilities who were unable to maintain the expectations in production were considered a burden.¹⁶ Assumptions were made that individuals with disabilities—especially those with intellectual and/or developmental disabilities (IDD)—were incapable of participating in and furthering the goals of society.¹⁷ The connection between capitalist success and assumed happiness is prevalent in many aspects in our society. In the United States, the idea of happiness is not only linked to financial success but dependent on it. The idea that individuals with IDD or other disabilities could be happy in participating in society in a variety of ways—including through meaningful employment—did not lend itself to ableist views of productive lives.¹⁸

The Eugenics Movement

Equating a “good” person with a “productive” person was foundational in the eugenics movement¹⁹ Language was essential in the construction of normal and abnormal—by medicalizing disability it made disability a failure in the body and thus abnormal.²⁰ Language of deficiency and suffering highlighted the need to eliminate or mitigate disability. The eugenics movement utilized pseudoscience and promulgated fear in order to further the idea of social and moral reform through the elimination of characteristics or genes that were deemed impure or not beneficial to society.²¹ For people with disabilities, this was often done through forced or coerced sterilization as well as killing or abandoning infants with obvious disabilities.²² Forced or coerced sterilization was legal through the mid-twentieth century in certain parts of the United States, allowing for individuals in “helping professions” to advocate for the betterment of society through sterilization.²³ The concern that destitution was hereditary

¹⁵ Ibid.

¹⁶ Hiranandani, “Towards A Critical Theory Of Disability In Social Work,” 1-14.

¹⁷ Johannes Reinders, Tim Stainton, and Trevor R. Parmenter, “The Quiet Progress Of The New Eugenics. Ending the Lives of Persons with Intellectual and Developmental Disabilities for Reasons of Presumed Poor Quality of Life,” *Journal Of Policy And Practice In Intellectual Disabilities* 16, no. 2 (2019): 99-112.

¹⁸ Reinders, Stainton, and Parmenter, “The Quiet Progress.”

¹⁹ Laurie Cooper Stoll and Justine Egner, “We Must Do Better: Ableism And Fatphobia In Sociology,” *Sociology Compass* 15, no. 4 (2021).

²⁰ Stoll and Egner, “We Must Do Better.”

²¹ Reinders, Stainton, and Parmenter.

²² Ibid.

²³ John Welshman, “The Social History of Social Work: The Issue of the 'Problem Family', 1940-70,” *British Journal of Social Work* 29, no. 3 (1999): 457-476.

informed the use of eugenics and forced sterilization for both disabled and non-disabled individuals.²⁴

In 1923, the Eugenics Society established a committee to fund and complete research projects with this aim.²⁵ In one of the best-documented sterilization programs in the United States, the North Carolina sterilization program utilized the 1933 eugenics law to authorize sterilization based on “mental disease, ‘feeble-mindedness,’ or epilepsy.”²⁶ Castles highlights the complicity of those in helping professions on a board consisting of “the commissioner of public welfare, the secretary of the state board of health attorney general, the chief medical officer of Dorothea Dix State Hospital in Raleigh, and a rotating fifth member from other state institutions.”²⁷ In some institutions throughout the United States, social workers were on staff or consulted in the sterilization process.²⁸ Family members were often coerced into making this decision—if they were consulted at all.²⁹ Often, these family members were informed that it would not only protect their children from pregnancy but that it would decrease sexual interest and protect them from sexual violence.³⁰

The eugenics movement—and the focus on forced or coerced sterilization—laid the foundation for current approaches to serving women with disabilities experiencing violence. Assumptions about sexuality or sexual ability, as well as the potential for intimacy and consent, have further prevented women with disabilities from accessing care when experiencing violence. Both preconceived notions and lack of knowledge have perpetuated stigma and inadequate care in serving women with disabilities.

The Continuum of Violence

The “continuum of violence” is a concept used to explain the complexity of violence for a woman experiencing abuse.³¹ Different types of abuse are often co-occurring, exacerbating and influencing one another.³² Eriksson & Ulmestig also argue that the experience of a marginalized

²⁴ Welshman, “The Social History of Social Work”

²⁵ Ibid.

²⁶ Katherine Castles, “Quiet Eugenics: Sterilization in North Carolina’s Institutions for the Mentally Retarded, 1945-1965,” *The Journal of Southern History* 68, no. 4 (2002): 849-878.

²⁷ Castles, “Quiet Eugenics” 852.

²⁸ Ibid, 849-878.

²⁹ Ibid.

³⁰ Ibid.

³¹ Marie Eriksson and Rickard Ulmestig, “‘It’s Not All About Money’: Toward A More Comprehensive Understanding of Financial Abuse in the Context of VAW,” *Journal of Interpersonal Violence* 36, no. 3-4 (2017): 1625-1651

³² Eriksson and Ulmestig, “It’s Not All About Money.”

individual's identity (socioeconomic class, ethnicity, age, disability, etc.) impacts the lived experience for financial abuse.³³ Gender, race, and ethnicity are part of a larger organization of hierarchies—establishing power and privilege in connection to certain bodies.³⁴ These hierarchies are evident within the continuum of violence, recognizing that women of marginalized identities are at a higher risk for violence.

Within the continuum of violence are disability-specific risk factors and disability-specific abuse. Women with disabilities experience a variety of abuse, including financial, physical, sexual, and verbal abuse.³⁵ Disability-specific abuse, including withholding medications, denying access to mobility services, neglecting personal care, and preventing access to doctor's appointments, are often ignored or not interpreted by service providers as abuse.³⁶ Perpetrators may also use disability-specific verbal abuse in order to devalue the individual and make them feel that they are unable to leave.³⁷ This has led to longer periods of abuse and increased risks for chronic illnesses and exacerbated disability symptoms.³⁸ Perpetrators may also use the threat of hurting or removing a victim's child from the home, leading to increased cooperation in an abusive relationship.³⁹ Women with disabilities can be restricted from full social participation, which increases their invisibility in the social sphere leading to increased abuse⁴⁰. Survivors may be unable to leave abusive situations because the physical spaces they may go—including shelters, community centers, or a family member's home—may be physically inaccessible or may not have the level of care they need.⁴¹

Numerous risk factors that can exacerbate or affect violence for women with disabilities include: sexuality and assumed asexuality, feelings of unworthiness, presumed and actual vulnerability, and lack of financial mobility. Examining these factors through the lens of the eugenics movement allows us to see patterns and connections in language and action.

³³ Ibid.

³⁴ Rosemarie Garland-Thomson, *Extraordinary Bodies* (Columbia University Press, 1996).

³⁵ Jennifer M. Mays, "Feminist Disability Theory: Domestic Violence Against Women with a Disability." *Disability & Society* 21, no. 2 (2006): 147-158.

³⁶ Sara-Beth Plummer and Patricia A. Findley, "Women with Disabilities' Experience with Physical and Sexual Abuse," *Trauma, Violence, & Abuse* 13, no. 1 (2011): 15-29.

³⁷ Andy Johnson, Ruth Nelson, and Emily Lund, *Religion, Disability, And Interpersonal Violence* (Cham: Springer International Publishing, 2017).

³⁸ Plummer and Findley, "Women with Disabilities."

³⁹ Laura Platt, et al., "The Role of Gender in Violence Experienced by Adults with Developmental Disabilities," *Journal Of Interpersonal Violence* 32, no. 1 (2016): 101-129.

⁴⁰ Mays, "Feminist Disability Theory."

⁴¹ Johnson, Nelson, and Lund, *Religion, Disability, and Interpersonal Violence*.

Sexuality

This stigma regarding sexuality and the ability to have sexual or intimate relationships was a critical piece of the sterilization movement. Individuals with disabilities are often assumed to be asexual and aromantic.⁴² The misinformation on safety in regards to sexual assault has furthered the stigma in discussing sex and safety with individuals with disabilities.⁴³ There is a misconception that individuals with disabilities are likely to be perpetrators of sexual assault, when in reality individuals with disabilities are at a higher risk to be victims of sexual assault. Controlling sexuality and preventing intimate relationships were part of the forced sterilization movement, informed by and furthering the assumption that individuals with IDD were child-like and unable to experience sexuality.⁴⁴ This assumption has—incorrectly—furthered the idea that if individuals with disabilities cannot be sexual that they cannot be abused.

Feelings of Unworthiness

Women with disabilities have reported having lower standards, not believing that they deserve love, which has led to increased rates of abuse. They are afraid to lose their partners, and therefore they report they are more willing to stay in abusive partnerships.⁴⁵ Recognizing the connection between feelings of unworthiness and the value assigned to the disabled body is critical. Value is assigned to people with disabilities multiple ways: whether or not someone can participate in labor and the ability to reproduce and or/engage in sex are two ways in which people with disabilities—and especially women with disabilities—have been assigned value in society.

Presumed and Actual Vulnerability

Women with disabilities are at a higher risk of abuse due to both presumed and actual vulnerability⁴⁶ Lack of mobility resulting from disability can make an individual more vulnerable and therefore more susceptible to abuse. Additionally, women with disabilities may be of a lower socioeconomic status, isolated, and have health limitations, leading to increased

⁴² Mitchell S. Tepper, "Sexuality and Disability: The Missing Discourse of Pleasure," *Sexuality And Disability* 18, no. 4 (2000): 283-290.

⁴³ Tepper, "Sexuality and Disability."

⁴⁴ Castles.

⁴⁵ Plummer and Findley, "Women with Disabilities."

⁴⁶ Kirsten A., Barrett, Bonnie O'Day, Allison Roche, and Barbara Lepidus Carlson, "Intimate Partner Violence, Health Status, And Health Care Access Among Women With Disabilities," *Women's Health Issues* 19, no 2 (2009): 94-100.

dependency on a caretaker or partner.⁴⁷ Some individuals report not coming forward due to a fear of losing their independence after receiving attention from Adult Protective Services, which could lead to being placed in a more restrictive environment.⁴⁸

Individuals who are perceived as having cognitive disabilities are at an increased risk for violence.⁴⁹ There is an increased risk when a perpetrator feels that they could easily manipulate, abuse, or take advantage of someone with a perceived cognitive disability. Individuals with lower or limited cognitive ability are more likely to struggle finding services, either because they do not know they exist or they do not know how to access them.⁵⁰ Individuals with IDD may need additional support in assessing certain social situations, which can lead to a lack of awareness regarding abusive situations and relationships.⁵¹ When communication difficulties are present or individuals are in an institutional setting, there are higher rates of abuse.⁵² Additionally, those with an increased risk of dependence on their abuser, often aligning with those with cognitive impairments, have an increased risk for abuse.⁵³ In the early twentieth century, fears of women with disabilities reproducing fueled the call for sterilization. These women were often coerced or forced—at times by their own families.⁵⁴ Women with disabilities are at an increased risk of violence today due to both perceived and actual vulnerability, echoing the vulnerability of women with disabilities in receiving sterilization and forced medical care during the course of the eugenics movement.

Lack of Financial Mobility and Abuse

Economic and financial abuse is a unique aspect of intimate partner violence. By controlling someone's finances or ability to earn money, an abuser is able exert control in a more covert and often imperceptible way.⁵⁵ Financial abuse is often hidden or underreported due to a lack

⁴⁷ Josephine W. Hahn, Marie C. McCormick, Jay G. Silverman, Elise B. Robinson, and Karestan C. Koenen. "Examining The Impact of Disability Status on Intimate Partner Violence Victimization in a Population Sample." *Journal of Interpersonal Violence* 29, no. 17 (2014): 3063-3085.

⁴⁸ Johnson, Nelson, and Lund, *Religion, Disability, and Interpersonal Violence*.

⁴⁹ Plummer and Findley.

⁵⁰ Heidi L. Scherer, Jamie A. Snyder, and Bonnie S. Fisher, "Intimate Partner Victimization among College Students with and without Disabilities," *Journal of Interpersonal Violence* 31, no. 1 (2014): 49-80.

⁵¹ Patricia A. Findley, Sara-Beth Plummer, and Sarah McMahan, "Exploring the Experiences of Abuse of College Students with Disabilities," *Journal Of Interpersonal Violence* 31, no. 17 (2016): 2801-2823.

⁵² Mays.

⁵³ Ibid.

⁵⁴ Castles.

⁵⁵ Eriksson and Ulmestig.

of standard definition and lack of interest when researching intimate partner violence.⁵⁶ Women with disabilities are often already at an economic disadvantage compared to nondisabled women. Women with disabilities are more likely to receive lower wages, experience occupational segregation, and are prevented from obtaining employment. The focus on efficiency can prevent accommodations for people with disabilities, therefore increasing the financial gap between people with disabilities and non-disabled people. This connects to the value placed on those able to contribute in economic systems, furthering the assumptions of the eugenics movement in assigning worth related to economic value.⁵⁷

In examining the ways in which the view of the disabled body and the eugenics movement continue to inform our understanding of intimate partner violence for women with disabilities, it is necessary to examine the ways that those in helping professions can further these assumptions and ultimately perpetuate harm.

Helpers as Oppressors

Those in helping professions have often acted as enablers of violence, either not recognizing indicators of violence due to preconceived notions of disability or enacting violence in order to effectively mitigate disability. The trajectory of social work is a prime example of how paternalism has promulgated misinformation in an effort to delineate who is considered “deserving” and “undeserving” in receiving services.

The Charity Organization Society (COS) movement is considered a major part of the foundation of the social work profession. Workers in a COS would determine the worthiness of an individual or family receiving aid, creating a designation between the worthy and unworthy poor.⁵⁸ The delineation between the deserving and undeserving poor elevated those that were unable to work but deserving of charity, including children, widows, and the disabled. Those that were undeserving, such as able-bodied men who were not working, were considered lazy.⁵⁹ However, within this delineation, there were value judgments made regarding how aid is provided. As social work developed into a profession, workers themselves focused more on

⁵⁶ Gillian Dalley, Mary Lynn Gilhooly, Kenneth Gilhooly, Michael Levi, and Priscilla Harries, “Researching the Financial Abuse of Individuals Lacking Mental Capacity,” *The Journal of Adult Protection* 19, no. 6 (2017): 394-405.

⁵⁷ Coco.

⁵⁸ John Ehrenreich, *The Altruistic Imagination* (Cornell University Press, 1985).

⁵⁹ Ehrenreich, *The Altruistic Imagination*.

individual pathology rather than societal experiences.⁶⁰ Aims to professionalize were intrinsically tied to the feminine foundation of social work: social workers wanted to legitimize and elevate the profession by creating rules, regulations, and standards. These standards were developed from existing patriarchal institutions and knowledge bases, therefore connecting social work to institutions of oppression rather than self-determination.

Social workers existed in a unique space: they aimed to alleviate the burden on marginalized individuals but also required the continuation of this burden in order maintain their work. This led to an interesting dynamic in which social workers were examining ways to support clients while maintaining certain aspects of the status quo. Additionally, social workers would attempt to address social issues by implementing values that were deemed to benefit society, such as striving for independence and participating in the labor force.⁶¹ The goal of these values was to alleviate the “burden” on society.⁶² By maintaining that poverty was individual rather than societal, social workers furthered the notion that responses should be individual rather than societal.⁶³

This view relates to the pathologizing of disability required in the medical model.⁶⁴ While the social model of disability suggests that the problem is not individual but rather society’s failure to accommodate individuals with disabilities, the medical model posits that the disability is inherent to the individual and therefore should be addressed by alleviating or curing symptoms.⁶⁵ Social work, like many helping professions, began working with disability from a medical model framework, centering the limitations of disability rather than the limitations of society.⁶⁶

Social workers are part of and often reinforce a system that requires complicity, and this creates an environment in which social workers may be unable to truly advocate for social change without negatively impacting their own career. A prime example of this complicity is the sterilization movement of women with disabilities. Social workers were often part of care

⁶⁰ Ibid.

⁶¹ Robert Humphreys, *Poor relief and charity 1869-1945* (Palgrave Macmillan, 2001).

⁶² Humphreys, *Poor relief and charity*.

⁶³ Ibid.

⁶⁴ Ibid.

⁶⁵ Hiranandani.

⁶⁶ Ibid.

teams or directly working with individuals with disabilities.⁶⁷ Involuntary or coerced sterilization limited the reproductive capabilities of women with disabilities in the nineteenth and early twentieth centuries as part of the eugenics movement. Advocates of sterilization argued that this ultimately benefited society and relieved the women of the burden of having and raising a child.⁶⁸

As social work has moved toward a resilience model, it has further incorporated the social model of disability. Despite best intentions, those in helping professions still operate under false assumptions that can ultimately be detrimental to serving women with disabilities. Those working in disability organizations often invalidate or discount women with disabilities when they come forward regarding abuse, as they are not prepared to identify or combat abuse.⁶⁹ There are still assumptions that women with disabilities are asexual and therefore unable to experience physical or sexual abuse.⁷⁰ Domestic violence agency workers and those working with people with disabilities are less likely to identify the abuse due to assumptions of asexuality and intimacy.⁷¹ The paternalistic and patriarchal foundations of social work—and many other helping professions—continue in current practices, operating from assumptions of incapability and helplessness. Social work must grapple with its history in order to address current implications for practice and policy change in serving women with disabilities.

Conclusion

Women with disabilities are at an increased risk for intimate partner and domestic violence due to numerous disability-specific factors. Further underlying this risk is the history of the eugenics movement, which perpetuated inaccurate information and stigma that informs our conceptions of disability today. Helping professions, such as social work, have often utilized medicalized and pathologizing terms, which further categorized women with disabilities as the “other.” Social work furthered its goal as a profession while fostering the belief that disabled bodies were less worthy than non-disabled bodies. Devaluing women with disabilities has only exacerbated their risk for violence. By recognizing the connection of gender and power in the

⁶⁷ M^a de las Mercedes Serrato Calero, Ángel M. Delgado-Vázquez, and Rosa M. Díaz Jiménez, “Systematized Review and Meta-Synthesis of the Sterilization of Women with Disabilities in the Field of Social Science: From Macroeugenics to Microeugenics,” *Sexuality Research and Social Policy* 18, no 3 (202): 653-671.

⁶⁸ Calero, Delgado-Vázquez, and Jiménez, “Systematized Review.”

⁶⁹ Ravi K. Thiara, et al., *Disabled Women And Domestic Violence* (London: Jessica Kingsley, 2012).

⁷⁰ Plummer and Findley.

⁷¹ Platt et al.

historical constructs of disability and sexuality, we can finally begin to grapple with the beliefs that steered the eugenics movement and ultimately continue to effect violence today.

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Conceptual and Political Lives of Reasonable Accommodation in India

Shilpaa Anand¹

Offices of disability services in Indian institutions of higher education, either known as enabling units or equal opportunity cells are met with two tropes of responses from the members of the campus community – the sympathy-charity trope and/or the suspicion-of-misuse trope. In this paper I review instances that manifest these tropes of affective reactions, where one is sidelined as non-threatening and the other is distanced as threatening.

An important point of departure for some observations made in this paper is James Staples's investigation of the entanglement of disability and charity which drew on ethnographic fieldwork in Hyderabad, in India identified charity as a "prism through which disability, as it is broadly conceived in India, might be explored and better understood" ("Doing", 2018, 130). Staples's work responds to earlier disability scholarship (Stiker, 2002) that had proposed that disability was historically ensconced within the category of poverty and thereby responded to by acts of charity, until it later became a medical category. Staples's fieldwork in Hyderabad reveals that disability's entanglement with charity is intact in the contemporary Indian context because philanthropy is intrinsic to Indian ways of going about the world. This paper proposes that disability's entanglement with charity has less to do with any cultural-material circumstances of the Indian context and probably more to do with charity being conceptually dependent on disability (Staples, 2018).

Responses to disability on campus:

This section presents the experiences of a committee that was nominated to create a cell that would address disability concerns in a university campus in Hyderabad. Over the period of two and a half years, the committee consisted of eight to fifteen members at different points in time. All the members had been nominated by the administration without being consulted. Of this, the most active members were a motley crew of 7 to 8 people that consisted of a combination of disabled and non-disabled women and men. It was apparent that charity (here a loose umbrella term), rather, a charitable attitude, worked covertly however rhetorically in the way that the committee was instituted and the way it was responded to by other members of the university community. The UGC (University Grants Committee), a governing body that creates

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guidelines for the functioning of institutions of higher education in the country had mandated the establishment of units that would fulfil the same role as offices of disability services in the U.S.A. - to make institutions of higher education accessible to people with disabilities and adopt a disability inclusive framework. The committee in my university was an attempt to adhere to the UGC's guidelines. It had been instituted to check a box that would improve the rating of the university at the time of assessing it for state funding.

When the committee was constituted, duties assigned to it included 'awareness-raising' and 'counselling'. Though it was not stated, it was assumed that the committee/unit would function in relation to the student body – that is, raise awareness among the students and counsel them. However, the disabled community on campus believed that the task of the committee was to serve as an activist core-group and a service provider. Reflecting on the committee's activities years later leads to the observation that an institutional mechanism derived from a rights-oriented disability framework, the cell, evolved at the intersections of affect-based interpersonal relations and institutional mandates.

Many of these events were perceived as do-goodery, no matter what the intention of the cell was and even though the talk was about disability discrimination and protections available in the UNCRPD. Soon one learnt that some attendees of the talks were there to gain a moral value by being seen at the event. When top administrators attended the rally on 3rd December one year, they insisted on pushing the wheelchairs of the wheelchair users. Photos were taken of them pushing wheelchairs and shared dutifully on social media platforms. In a speech made to inaugurate the event, an administrator strongly recommended that we stop using the word disability in the name of the cell and adopt the phrase 'differently-abled' as it was "not negative". On the same occasion, a senior professor acknowledged that she attended rally because "it is a matter that is close to my heart." While this professor had indeed been a frequent attendee of most of cell's events, the 3rd December rally drew forward a wide variety of long-time faculty members of the university, many of whom had hardly attended other awareness-raising programmes. While this surprised the committee, we realized that the surprise visitors were present to be seen by the top administrators. They were also checking off a box – they wanted to be perceived by the administration as moral or socially conscious.

The university had determined the duties of the committee as 'awareness-raising' and 'counselling'. Both these duties were perceived as 'non-threatening' and it was hoped that the disabled constituency could be appeased through these gestures. Problems emerged when the

committee made demands for reasonable accommodations in relation to various disabled members – these demands required the administrative body to change routines and norms. Of such demands the three that stood out were: the demand by students of the Education department for accessible vehicles or travel allowance that would cover their commute from the university to the schools where their practical sessions were being conducted; the demand of students for accessible washrooms in the library; the non-teaching staff's demand for the PH category employment positions to be advertised so that they could apply for their positions – all their positions were of a contractual or temporary nature. All demands requiring reasonable accommodations were rarely addressed and when addressed, the accommodation sought was routed to another department or office to be addressed. A previously non-threatening docile unit had turned out to become a threat to the distribution of the university's resources!

Affective realities of disability in higher education:

Reasonable accommodation in international and Indian disability law enables diverse accommodations for people with different access needs. Accommodations address barriers created by a wide variety of norms and practices of standardization. That the UNCRPD does not describe the kinds of accommodations that can be made has strengthened its underlying goal of non-discrimination by supporting different kinds of claims for accommodations. Access needs of disabled people vary across impairments. Additionally, people with the same impairment may have different access needs based on gender, caste, class, region and religion. An accommodation is based on the experience of disability and not only the assumed impairment effect. Embedding the reasonable accommodation clause in law follows a long history of informal measures adopted in educational and employment establishments and the non-recognition of disability support as a responsibility of the establishment. According to Amita Dhanda, the clause is grounded in the principle of inclusion and addresses the exclusionary potential of norms that do not account for disabled people's experiences. Two features are noteworthy. One, the institutionalization and practice of certain norms requires that they be customized in order to be accessible to the different needs of persons with disabilities. Two, given that it is not negotiable, any change that enables inclusion is considered reasonable as it has significant implications for enabling diversity. To quote Dhanda, "If non-implementation of an accommodation could prevent a person with disability to partake of the right, then irrespective of cost, reasonable accommodation as an integral limb of the right to equality has to be provided. If, on the other hand, non-acceptance of the accommodation does

not have such consequence, then it would be reasonable to refuse accommodation” (Dhanda, 2016, 454).

In order to reflect on the discourse and enactments of reasonable accommodation, it may be necessary to reflect on the conceptual history of the clause. Reasonable accommodation draws on international human rights law that bases equality on two features - non-discrimination and reasonable differentiation. The concept of reasonable accommodation emerged within civil rights legislation in the United States, in relation to discrimination on the grounds of religious practice. According to the Civil Rights Act of 1968, employers are required to provide “reasonable accommodations” to an employee’s need to observe or practice some feature of their religion. The caveat of not causing the employer’s establishment “undue hardship” while making the accommodation is included here. Extending this to the present Indian context would mean that, for instance, a student should be allowed to wear a hijab to the school or college unless the institution’s authority can prove that wearing of a hijab is fundamentally incompatible with spaces of public education (Bhatia, [The Essential Religious Practices Test and the Inversion of Agency: Notes from the Hijab Hearing](#)). The concept of accommodation has thus been significant in the legal and administrative discourse related to the protection of the rights of religious minorities. However, it may not be inappropriate to note that the genealogy of the reasonable accommodation clause ironically betrays its conceptual emergence as threat-bearing given that the dominant anti-Muslim sentiments that jealously guard right wing extremist politics in present-day India, continually frames religious minorities as threatening. The discourse of providing reasonable accommodations are fraught with tensions evident in the rhetoric of provisions being misused -the fear that the giving of an accommodative inch would result in a whole yard being taken.

Reasonable Accommodation and its Affective Politics

In the Vikash Kumar case (Vikash Kumar v. Union Public Service Commission), the Supreme Court of India upheld reasonable accommodation by ruling that a candidate with dysgraphia who was appearing for the Indian Civil Services Examination was entitled to a scribe. The UPSC’s reason for not readily accommodating the candidate was based on the rules of the examining body which stipulated that only applicants who were blind or had locomotor disability or cerebral palsy could claim the accommodation. Additionally, disabled candidates with an impairment effect measured at or above 40% were eligible for the accommodation. The judgement relied on the provisions of the Rights of Persons with Disabilities Act (2016) in

compliance with the UNCRPD (2007) underscoring that it was only through the provision of reasonable accommodations that non-discrimination towards disabled people could be practiced. The court further clarified, relying on the *Jeeja Ghosh v. Union of India* (2016), that restoring equality is constituted not only through non-discrimination but through positive rights as well, such as reasonable accommodation. In doing so the court ensured substantive equality. Arguing that the denial of reasonable accommodation amounted to disability-based discrimination, the court claimed that the provision of a scribe ensured that the disabled candidate to overcome an exclusionary barrier without placing “disproportionate burden” on the examining body. Fulfilling the reasonable accommodation request in this situation would not place the undue burden of adapting the examination environment entirely in a way that would enable it to provide equality of opportunity to all persons with disabilities.

The state’s (UPSC) concern that the provision of a scribe would give the candidate an undue advantage in the exam was dismissed on the ground that there was inadequate data to substantiate such a concern. Furthermore, the court cautioned that the unsubstantiated suspicions of this nature reinforced stereotypes about people with disabilities. It encouraged the state to evolve policy in consultation with people with disabilities. Analyzing the judgment, Amita Dhanda finds that the court has upheld the individual nature of the reasonable accommodation clause, recognizing that it is a right guaranteed to all persons with disabilities, that the nature of reasonable accommodation cannot be predetermined and can be decided on the basis of the individual’s access need. She claims that the court’s decision based on the appellant’s plea proves that any decision ensuring the inclusion of people with disabilities is reasonable.

The court’s decision reflects that the court bore the burden of demonstrating how the provision of a reasonable accommodation would not place an undue burden² on the examining body. In doing so, the court was setting aside the concept of universal design in favour of individual inclusion. Dhanda argues that in including every person with disability, the essence was to treat each individual as a class of their own while resolving claims for reasonable accommodation.

² It must be noted that the clause, “not imposing a disproportionate or undue burden”, seems to be discussed more extensively in court cases than the clause about “necessary and appropriate modification and adjustments” to include people with disabilities.

Underlying this case is a problem of mistrust of the category of disability. In the Vikash Kumar case, while ruling in favour of the accommodation, the judges pointed to the nature of social discrimination that is related to the denial of reasonable structural accommodation. Denying accommodation on the suspicion of misuse betrays something about the inherent assumptions that are made for accommodation claim. In another case, on that concerns the Medical Council of India, a body that governs medical education, a similar pattern becomes evident.

The Medical Council of India implemented fresh guidelines in 2018 deeming persons with a range of disabilities ineligible to accessing higher education in the medical sciences and its affiliate fields. Persons with learning disabilities, visual impairment, hearing impairment and autism were considered ineligible as per the affirmative action measure that is in place for the National Eligibility cum Entrance Test for higher education in Medicine. One of the concerns here was that children and young adults with learning disabilities who had accessed reasonable accommodation measures in their schools in certain states were not considered eligible for reasonable accommodations in medical education. In fact, the claims were not even being considered as reasonable ones in the context of medical education thus exposing the very conceptualization of medical education that informed medical establishments. Disabled people were not included in the decisions that were made - it was the experts who made the pronouncements.

Satendra Singh, a medical professional and a scholar of Medical Humanities discusses the problem of excluding candidates with learning disabilities from accessing the medical entrance tests. When the fresh guidelines were introduced by the Medical Council of India, Specific Learning Disabilities, a category of disability included in the RPD Act was considered to be ineligible on the basis of conclusions made by a psychiatrist. The conclusion was based on the claim that there were no objective criteria or methods established to quantify cognitive status or even mental illnesses. Given this, the expert argued, there was a higher chance of parents of young adults trying to get fake certificates. Singh observes that disabled people were, once again, not consulted in the policy-making process.

In a related case, the presence of Congenital Colour Vision Deficiency (CCVD) was used as a reason to disqualify students for opting for certain specializations in medical education. However, it was found that CCVD cannot be standardized as its lived experiences vary widely. Additionally, the test may not determine how an individual with this condition may experience it in real life. This cannot disqualify a person from pursuing a field of specialization in medicine.

Upreet Dhaliwal argues that the spirit of reasonable accommodation can be employed in enabling the students to develop their systems of colour recognition.

That the fear of misuse threatens every opportunity for a reasonable accommodation claim to be fulfilled is remarkable. The psychiatrist who served as the expert and pronounced that people with learning disabilities did not qualify as candidates for medical education stated their apprehension that the increasing number of students classified as having learning disabilities at the high school level in a few states was indicative of a misuse of the diagnostic category.

Time and again it becomes apparent that accommodations are conflated with dole outs and it is perhaps this inherent conceptualization of disability-in-charity that results in situations where establishments in charge of providing safeguards and enabling disabled people as rights bearers are overcome by speculation about the truth-claims about disability.

A curious binary of affective responses animates the theory and practice of reasonable accommodation in India – between charitable action and the suspicion of misuse. While this paper is an initial survey of the nature of the entanglement of disability and charity, it is driven by the need to re-examine an existing framework that operates within the DS discourse – that disability has historically been conceptualized as operating within the moral domain before moving into a biomedical domain and then later reconceptualized as a social-contextual category. This framework implies that disability is a substantial enough concept to have transformed in keeping with historical-material and epistemic shifts. What this framework does is it assigns disability the status of an independent concept. Nevertheless, taking a cue from other history-of-ideas investigations, it may be imperative to recognize that one concept is held in place by other concepts and while they become strong or weak based on material and cultural contexts, their conceptual interdependence cannot be belittled.

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Reasonable Accommodation and Politics of Care in an Indian University

Meghana Rao¹

Let me begin with an anecdote that happened recently in an Indian University. An Undergraduate student with an undiagnosed physical disability reached out to the administration because each large building in the University campus had only one ramp and she had to walk a lot to enter her classrooms which was leaving her exhausted, delaying her entry into classes and leaving her unable to focus in class.

A representative from the administration met with the student and listened to her concerns. He was, as the student mentioned to me later, “very nice, calm and patient”. After about thirty to forty minutes of conversation, he told her what help he could provide on behalf of the University. He said that he would provide a number that she could call 20 minutes before her classes started and they would send a buggy to her which would pick her up and drop her off to her next destination. Importantly, the student was informed that she could not share the buggy ride with any of her friends since this provision was made only for her because of her disability.

She left the meeting with mixed emotions. The student felt that she would be isolated if her friends could not share the ride with her. Her friends would be together, while she had to take the buggy alone. She was even embarrassed by this proposal. Simultaneously, she felt that the person she spoke to was very nice, patient and caring about her concerns.

I chose this anecdote because it is not necessarily unique and is probably reflective of a more (quote-unquote) ‘sensitive’ higher education institutional response in India. The University attempted to make some form of reasonable accommodation (henceforth RA) in the form of a buggy and it demonstrated a form of care which we can see by the administrator spending time listening to this student’s concern and coming up with a solution that the University felt was adequate. However, it left the student with disability dissatisfied and she eventually decided that it was better for her *not* to call for the buggy and instead rely on the support that her friends provided for her to reach her classes. She explained that she went to the administration with an intention of asserting her rights as a person with disability but the response she felt was one of benevolent care.

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In this paper, I will unpack two key aspects that have emerged in this anecdote: (1) the complex outcomes of the use of the RA principle and (2) the nature and politics of care in the context of RA. I look at the relationship between reasonable accommodation efforts and politics of care by reading this anecdote through the scholarship on reasonable accommodation and Black and Women of Color (WoC) feminist scholarship on care. In reading the RA principle through the lens of radical feminist care politics, I hope to push the boundaries and broaden the scope of the use and interpretation of RA principle.

Reasonable Accommodation and its outcomes

The RA principle began to gain momentum in India only after India signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007, and ratified it in 2009. The principle of RA as articulated in the UNCRPD means “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”.² Amita Dhanda, a renowned disability rights activist and lawyer explains, “The principle of reasonable accommodation by focusing on outcomes allows general norms to be so customized that they result in inclusion. The principle is general and universal as it aims to obtain substantive equality for all. This generality is in no way discounted by the fact that the application of reasonable accommodation shall always be individualistic and particular.”³

Going back to the anecdote mentioned earlier, the university representative made what he thought was the “necessary and appropriate modification and adjustments” to ensure that the concern raised by the student with disability was addressed. He changed the general norms of the University which did not have a buggy service for students, to accommodate this particular student to make the space more inclusive while “not imposing disproportionate or undue burden” on the institution. Abiding by the RA principle, he provided the individual with a solution that addressed (at least in part) her apparent need. However, this particular form of accommodation brought to the forefront the individualistic nature of RA.

² “Article 2—Definitions, Convention on the Rights of Persons with Disabilities,” Office of the Commissioner-United Nations Human Rights. Accessed on January 2022,

<https://www.ohchr.org/en/hrbodies/crpd/pages/conventionrightspersonswithdisabilities.aspx>

³ Amita Dhanda, “Reasonable Accommodation for all,” *Cafe Dissensus August 14, 2016*

<https://cafedissensus.com/2016/08/14/reasonable-accommodation-for-all/>

The focus of RA solutions on individuals in this context comes in the way of addressing another important aspect of the UNCRPD which is the “recognition of the importance of effective participation in society on an equal basis with others”.⁴ The accommodation provided by the University addressed the disability related physical impairment while ignoring the experience of disability holistically—the student’s social life and experience of the educational institution. Although the RA principle is designed to address all the requirements of the person with disability, in this context, it is only partially used to address her impairment and not her social participation.

Politics of Care

The second important articulation made by the student in the anecdote mentioned earlier was that of care. Within the anecdote, the student emerged feeling that the administrator cared for her, however, he did not entirely understand her situation and needs. And significantly, she explained that she attempted to assert a human rights discourse, while the response was one of benevolent care. In this section, I unpack questions about care such as: Who shows care? What form of care is demonstrated? And what are its implications? More broadly, I will bring the politics of care scholarship to speak to the praxis of RA.

The politics of care has been scrutinized and its potential articulated by Black and WoC feminists to claim its revolutionary potential.⁵ Black and WoC feminists’ interest in care is rooted in the belief that care can be used to address recurring forms of exclusion and dominance. Building on Audre Lorde’s important idea of care as political warfare, several black feminist and WoC scholars have asserted the fact that to care is to uphold the right to survive.⁶ Politics of care, emerging from this location is understood as “a collection of principles, practices, and laws that facilitate communal gathering and the governance of polities”.⁷ Woodly and Brown explain that “The politics of care is an approach to political thought and action that moves beyond the liberal approach which situates care as a finite resource to be distributed among autonomous individuals, or as a necessarily feminine virtue. Instead, those elucidating the politics of care for the contemporary era draw on rich interdisciplinary traditions and social

⁴ “Preamble The States Parties to the present Convention, Convention on the Rights of Persons with Disabilities”, Office of the Commissioner-United Nations Human Rights. Accessed on January 2022 <https://www.ohchr.org/en/hrbodies/crpd/pages/conventionrightspersonswithdisabilities.aspx>

⁵ Audre Lorde, *A Burst of Light: And Other Essays* (Ithaca, NY: Firebrand Books, 1988; Mineola, NY: Ixia Press, 2017), 130; Sara Ahmed, *Living a Feminist Life* (NC: Duke University Press, 2017).

⁶ Lorde, *Burst of Light*; Ahmed, *Feminist Life*.

⁷ Deva Woodly et al., “The politics of care,” *Contemporary Political Theory* 20, no. 4 (August 2021): 890.

movements to theorize and practice care as an inherently interdependent survival strategy, a foundation for political organizing, and a prefigurative politics for building a world in which all people can live and thrive”.⁸ Miriam Ticktin states: “Care is an affective state, it's a form of practice, it's an ethno-political obligation. It's also located in the mundane and the everyday”.⁹ Care for Ticktin is less a prescribed set of practices, but more a form of political imagination which fuels hope and desire for transformative action.¹⁰ So, within such a formulation, politics of care is a politics of imagination -- one that brings in new collectives and new affiliations that are ultimately based on mutual respect and equality.

However, Ticktin and others have also demonstrated that care need not always have liberatory potential.¹¹ Studying humanitarian efforts that use a care discourse, Ticktin explains that expression of care could be hierarchical, reactionary and used to exert power which keeps the status quo and not challenge the systems of power and inequality. Similarly, disability studies scholarship and activism has also critically engaged with the complexities of care and questioned the idealization of the role of the carer (often assumed to be a women) and the normative notion that having a disability only means being a recipient of benevolent care.¹² In framing care through this lens, this perspective often neglects the experiences of the receiver of care who might resist benevolent care for a variety of reasons such as feeling disempowered, undermined, or even abused by carers.¹³

Challenging this notion is the concept of interdependence. Mia Mingus explains interdependence as an approach that “...moves us away from the myth of independence, and towards relationships where we are all valued and have things to offer. It moves us away from knowing disability only through 'dependence', which paints disabled bodies as being a burden to others, at the mercy of able-bodied people's benevolence.”¹⁴ Tom Shakespeare, in the context of supported living, questions the notion that the aim of care is to promote autonomy and argues that “care and living arrangements are about more than autonomy and independence.

⁸ Woodly et al., “Politics of care,” 890.

⁹ Miriam Iris Ticktin, “From the Human to the Planetary,” *Medicine Anthropology Theory* 6, no. 3. (2019):136. <https://doi.org/10.17157/mat.6.3.666>.

¹⁰ Ticktin, “Human to Planetary,” 136; Woodly et al “Politics of care,”

¹¹ Miriam Ticktin, “Power and Politics of Care Panel” The New School, Accessed on November 06 2020.

Video, <https://www.youtube.com/watch?v=3MhLzpqH68> ; Hi‘ilei Julia Kawehipuaakahaopulani Hobart and Tamara Kneese, “Radical Care: Survival Strategies for Uncertain Times” *Social Text* 38, no. 38 (March 2020).

¹² Tom Shakespeare, *Disability Rights and Wrongs* (London and New York: Routledge, 2006), 135-152

¹³ Shakespeare “Rights and Wrongs,” 144-145

¹⁴ Mia Mingus, “Access Intimacy: The Missing Link” *Leaving Evidence*, May 5, 2011, <https://leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link/>

Preferences around care and support also reflect competing ideas of what a good life may involve.”¹⁵ When discussing care within the *Movement for Black Lives*, Deva Woodyly explains that this movement is grounded on a politics of structural care, where care is about healing social ills through social action and where interdependence is recognized and claimed as a fundamental fact.¹⁶

In addition, the disability movements building on the activism of queer and trans people of colour and black feminists, have brought to the forefront the concept and practice of healing justice which understands healing as a form of liberation and social justice. The healing justice perspective is a mode of analysis and action that recognises that oppression causes harm that is not solely instrumental and infrastructural. Oppression cannot simply be addressed through an instrumental lens—via demands from rights and questioning of material deprivation, but importantly it causes psychological bodily harm and addressing this harm requires actions of care that are both personal and political.¹⁷

Coming back to RA, as mentioned earlier, it straddles two principles: (i) its goal is to obtain substantive equality for all by allowing general norms to be customized and (ii) the application of RA will always be individualistic and specific.¹⁸ Since the RA principle is explicitly designed to address individual experiences of disability, the institution(s) often solely recognise experience of disability as an individual concern and provide instrumental solutions as seen in the anecdote mentioned earlier. What is then lost in this picture is the significance of interdependence and a more fundamental fact that experience of disability ought to be understood within a larger socio-political, historical context of marginalization and not simply as an individual concern. Concerns raised regarding disability within Indian higher educational institutions, unlike their reaction to concerns regarding race in the US or caste in India, often receive an instrumental reaction and are not addressed as a social structural issue that ought to be addressed through an intersectional lens.

In conclusion, in this paper I have attempted to read RA through the lens of radical care politics and interdependence as articulated by black and WoC feminists and disability scholars.

¹⁵ Shakespeare, *Rights and Wrong*, 137.

¹⁶ Deva Woodyly “The Politics of Care with Deva Woodyly”, Accessed on August 02 2020 at <https://www.youtube.com/watch?v=ih6F6N9pg-A>

¹⁷ Woodyly “politics of care”; Leah Lakshmi Piepzna-Samarasinha, “A not-so-brief history of the healing justice movement, 2010-2016” *Moving Image Culture Etc.* Accessed on January 05 2022.

¹⁸ Dhanda, “Reasonable accommodation”

This highlights the fact that RA is often used to make instrumental gains and importantly, the principle (as it is often implemented in Indian Higher educational institutions) does not recognise the experience of students on campus as one of interdependence. Institutions often invoke the ‘undue burden’ aspect to avoid widening the definition of RA. This narrow implementation of the RA principle has two primary consequences: (i) a lack of acknowledgment of the wide range of experiences of oppression that people with disabilities undergo in many of our education institutions and (ii) this partial recognition of the needs and rights of people with disabilities leads to providing solutions that often address material deprivation via affective notions of benevolent care. As healing justice thinkers have pointed out, solely addressing material concerns is not adequate, one has to recognise the social being and the radical care that is required to address all the physical and psychological experiences of marginalization.

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Reasonable accommodation, inclusion and the idea of a university: reflections from HEI spaces in India

Bindhulakshmi Pattadath¹

“For me, an idea of a university is a space where I do need to keep thinking about how I will accommodate myself, where I want to think only about my intellectual growth. But now when I go back to university, I need to think about how I manage my writing....my idea of the university is a space where I can study without thinking about all of these. It shouldn't be a place where I need to think too much about my needs and accommodation. I imagine a university where it is all inbuilt as part of the system” (AL, a researcher in disability studies and also identifies as a person with disabilities).

The UNCRPD article 2 defines reasonable accommodation as “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”(Conventions on the Rights of Persons with Disabilities, Article 2)

What are the conversations possible for bringing discussions on reasonable accommodation and inclusive pedagogical practices in university spaces, when experiences are framed across multiple margins of gender, ability, caste, class and so? While university spaces articulate reasonable accommodation as an institutional response for inclusive policy changes, are there conversations to reimagine the very idea of those ‘academic institutions’ which are often built through an ableist discourse of competency and merit? Can the idea of reasonable accommodation be a generative process across spatial and temporal dimensions? Do pedagogic experiments built on interdependent care relations (often read as informal care relations) provide spaces for such generative processes which may help reimagine and restructure the idea of ‘academic institutions’? Reflecting on personal narratives of young research scholars² and students who inhabit the higher education spaces in Indian academia, this paper makes an attempt to understand some of these crucial questions on reasonable accommodation and the idea of inclusion.

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² This paper greatly benefited from the conversations I had with AL and L two young researchers who occupy/cooccupied universities spaces in Indian higher education system.

Internalized ableism and relations of ruling

AL entered the university system as a person with chronic illness. According to her, there was always this **internalized ableism** within her which made her not actively seek support from anybody in the university.

“I thought, if I ask for that extra time I will be considered as not suitable for academia.” While AL explains this as internalized ableism, this is how universities are also constituted with the idea of merit and competence which efface the ethics of interdependent care relations. When the medical model prescribes the situated bodily differences of an individual as a discrete condition within them, it doesn't provide conversational possibilities beyond the medical model to address the structural inequities that create internalized ableism. This often attempts to treat structures as normative entities- so university with its larger objectives of disseminating knowledge and creating educated cohort to build nation-states and various other stated objectives. A student with embodied experiences of disability enter into that structures and often go through different structural hurdles on the way.

The assumption of experiences of disability as a discrete condition often emphasize the condition as an individual issue. This individualization of disability experiences attempts to see the conversation on accommodation as something required outside the normative structures of university spaces. So accommodation often gets translated as additional to the structure. Seeing disability as super-imposed to the structures of ability, doesn't challenge the internalized ableism within the structure. When AL explains the context of internalized ableism, let us also attempt to understand how this coat-rack view of seeing disability accommodation is something needed in addition to the already existing normative structures that get institutionalized within university spaces. The in-built normative structure does not get challenged within this context.

In order to explain this further let me illustrate another example. A few years back I met L as a young graduating student in a higher education institute in India. L is a first-generation scholar with a visual disability. “I had my doubts about my ability to cope with the university,” L says in our recent conversation around reasonable accommodation. “Instead of looking at our varied needs, we have been constantly asked to get adopted to the system.” This counter the very idea of reasonable accommodation. Instead of lessening the burden when students enter into structures built on discrimination, students' needs are often looked at within a discrete context and located disability within their bodies. Looking at bodies in this discrete context has its limitations. For eg, AL, another researcher whom I interviewed as part of this research,

entered the university space as a person with chronic illness but did not make the cut off of 40% disability. However, over the period of time, her condition changed.

“Teachers and friends were helpful on their own, but there were no resources to understand such uncertain situations. I had to arrange a disability certificate in a short time.” In a situation where disabilities are located within discrete notions of individual bodies, we ask these questions: How flexible is the academia to deal with the emerging situations when embodied experiences are a generative process? Can we consider reasonable accommodation as a one time process fixed over there? Or can it be something that is flexible and generative, taking into account the context(s)?

AL explains that it is very individual dependent.

Yes, it is very individual dependent. For example, a specific professor will support you. It is not that there is a whole lot of administrative structures that will support you. When you are sick there is a whole lot of process, you need to get a certificate from a doctor and you need to go through that kind of ‘gruelling’ process if you need that kind of support. Then there is like ‘you don’t look disabled, you don’t look sick’ ‘what is your problem, you don’t look disabled’...

This narration from AL further brings the question of how subjective embodied experiences are textually mediated in a governing world that makes sense of disability and reasonable accommodation only through coded knowledge. This **relations of ruling** (Smith 1987) (which translate as a ‘gruelling’ experience for AL) attempts to look at the disabled experience as an objective category that can be measured within the discrete idea of our bodies.

Smith introduces the concept of ‘relations of ruling’ (1987) while arguing for feminist sociology, which challenges the assumed coincidence of the standpoint of men and the standpoint of the ruling class by positioning ‘the everyday world as problematic. ‘Relations of ruling is a concept that grasps power, organization, direction and regulation as more pervasively structured than can be expressed in traditional concepts provided by the discourse of power. I have come to see a specific interrelation between the dynamic advance of the distinctive forms of organizing and ruling contemporary capitalist society and the patriarchal forms of our contemporary experience. “When I write ruling in this context, I am identifying a complex of organized practices, including government, law, business and financial management, professional organization, and educational institution as well as discourses in texts that interpenetrate the multiple sites of power” (Smith 1987:3).

University as a political space

Much has been written about university spaces and the politics that space occupied. Over the years, India has witnessed significant students movements that address the increasing curtailment of academic freedom, reproduction of caste and class hierarchies and its direct implications on students' lives. Shrinking spaces of academic spaces and neoliberal ideology also have a direct bearing on the lives of University students. Does the political nature of the university campus provide necessary articulations of disability? Do the conversations around gender, caste and class which have been there always overtly identify universities as political spaces? Does that idea of 'political' help individuals with disabled bodies navigate the system? Do the support structures students receive informally have a possibility to transform?

I draw here from the work of Nirmal Puwar (2001) to understand how **somatic norm** constructs and excludes identity from the apparently neutral spaces. AL describes the nature of political space she encountered in university H:

In university H, the discussion around disability was almost absent. There was obviously discussions around gender and caste. There was no discussion around disability as an identity category. So there was no visible political space occupied with the identity of disability. So for me, it was like there was someone studying disability as research, who would understand what is disability on a very individual level. Very rarely do we touch upon disability as an identity.

Unlike Puwar's notion of putatively 'neutral' space (2001), the university where AL studied was visibly political. Like any other space, somatic norms are reproduced within that space of hierarchy, however, embodied markers of caste and gender also disrupted that somatic norm. However, as AL expressed disability was marked outside those political markers. I may argue that this would be the larger context of situated politics of disability movement in India, which so far failed to make the fissures in the political space of university where caste and gender articulations have made significant fissures. Do we have a political movement marking disability as an identity category from Indian academic spaces like the way caste and gender politics are articulated? Unlike the psychiatric survivors' movement in the Euro-American context or in the context of the disability movement in British academia which paved the way to articulate social model of disability, in Indian academia, disability as an identity category is not yet made the epistemic fissures (Rice 2006).

The political nature of the campus should be an ideal space to have serious conversations around different socio-political movements and thus broadening the vision of the politics.

However, from AL's narrative, it was imperative that AL did not find enough synergy between different socio-political movements especially located within the spectrum of identity politics. For example, while university and Higher Education Institutes are the places where we see the recycling nature of the idea of meritocracy, the politics that emerged from the margins questioning the fundamental problems of merits could be an ideal place to broaden the conversation around competency and merit.

Informal care relations and building solidarity

What are the possibilities to bring solidarity from the political space of the university? In the absence of disability politics that are interlinked with other political movements in the university, where else are care relations formed? According to AL these care relations are always informal and located within the individual and their specific needs.

For example, AL was going through a transition stage from a chronically ill person to someone identified as a person with a disability vis-a-vis her embodied situated contexts are concerned during her research at University H. When the pressure to stick to submission deadlines emerged during her course, friends and other informal support structures created an enabling environment for her at an individual level. Do these informal care relations have the possibility to transform, change and subvert the idea of meritocracy and competency? Do they have the possibility to make alliances with larger political movements? Do they have the possibility to institutionalize inclusive care structures within universities?

During AL's term as a research student at University H, the university was going through a strongly emerged student protest as a result of the death by suicide of a young research scholar which was largely understood as an institutionalised murder as a result of caste discrimination in the university. This has resulted in a strong student political movement that had the potential to make a transformation in pan Indian context bringing various marginalized groups in a politics of solidarity. Where is disability as an identity category located in this context? AL does not see the possibility of seeing the solidarity building of disability as an identity category with other marginalized identities at this moment.

I do not see a possibility right now, because, for example, the caste discrimination became such a big issue at university H when R lost his life. From that, the whole student protest and movement emerged. I do not see that possibility with disabled identity.

One of the reasons for this could be the location of disability within the individual, more precisely the material-biological body of the individual compared to how other marginal identities are understood and located, particularly along the intersections of gender and caste. Of course, both these identity markers have gone through the long-drawn struggle to move out of the narrow identification of individual as incompetent vis-a-vis their marginalized bodies are concerned through significant political movement as well as through scholarship emerged with critical epistemological perspectives (the early struggles of feminist scholarship to challenge biological determinism loaded with androcentrism, literature from critical race theory and studies from anticaste struggles will help to develop this argument further). While critical disability scholarship made significant advancements in challenging the idea of the body as given or critically looking at the biological body, it still grapples with the overloaded medical model which shaped the early discourse of disability. Particularly in the conversations around reasonable accommodation, we are yet to see how we move out of marking disabled bodies outside the medical model. Though the social model of disability helps us to locate discrimination outside the biological body of individuals, the discussion on reasonable accommodation comes back with institutionalized **relations of ruling** which demands a textually mediated coded knowledge on disabled experiences. When the ideology of ability (Siebers 2008) shapes the discourse around norms through built spaces and movements in social spaces, any difference to those given norms is considered to be dealt with separately at an individual level and get invisibilized or individualized without any institutional mechanisms to restructure the given ableist norms. This does not provide a possibility for building political alliances and solidarity.

One of the ways to bring disability within the political space of the campus is through representations. The disability culture which can subvert the ableist norm comes through representations. Currently, accommodations are done as an afterthought, making ‘adjustments’ around compulsory able-bodiedness. As AL illustrates:

University sees disability only as an individual issue and makes ‘adjustments’ around that. It hasn’t moved outside the individual issue yet. I think any change needs to be there, the conversations should start from the disabled students, not as an individual issue but as a collective identity. Accessibility is not an individual issue. Now it is seen like oh! The law is there so we need to give wheelchair, or we need to give extra time for the exam, it is not like it is already imagined, giving accommodation and access is not imagined before itself. For that, we need more

disabled students and disabled researchers, more teachers with disability and people interested in doing research on disability.

Representation, both theoretically and materially, is one of the steps to subvert ableism. However, AL is also cautious about **overcoming narratives** that shape the ideology of ableism and meritocracy in university spaces.

A lot I heard in the university spaces. Even passing an exam with good marks is considered as ‘inspiring’! ‘Despite her condition, she did that! So much in spite of and despites are there! Taking a medical leave she finished her thesis. I heard that a lot! I have heard this from both teachers and students. For example, doing something on time is considered inspiring. Not taking extra time is considered an achievement.

Challenging these overcoming narratives which reproduce the meritocracy and ideology of ableism requires cultivating a disability culture in university spaces. While reservation requirements bring certain representational possibilities, the narratives emerging from the experiences of students in the campuses draw attention to the limitations of existing reservation policies in higher education when it comes to disability accommodation.

For example, when students enter into university spaces through a multiplicity of experiences, how do we bring in reasonable accommodation keeping in mind the intersecting identities? In the context of AL whose schooling and pre-university were in mainstream school compared to L who had gone through a special school education in the pre-university period. When entering into a university space, the experiences they bring in from these two spaces differ. How do we recognize these differences bringing inclusive policies in Higher education institutions?

The political atmosphere of university H helped AL to reflect on her own privileges and helped her to think about intersectionalities of identity.

After I left the university, I started thinking about all of these and also the intersectionalities of identities, how it affects people, now since I understood this how ableism works if I am going for a PhD, the first thing I am going to think about is how accessible is that university is. like I want to talk to someone like another disabled student who studied there. Such things I started thinking now. It’s been three years I have been thinking along that line. Also when you talk about privileges when it comes to reservations for disabled students, most of the time an upper-caste and class background person gets that. In fact, R’s incident (caste discrimination and subsequent suicide of the student) made me think about all of these issues.

AL brought in here a crucial issue of how the admission process in the university settings churn out competency and merit where disability becomes a distinct discrete identity and often perceived as outside the structures of other hierarchies. In the current context of Indian academic spaces, these conversations are essential in order to reimagine university and thus restructuring the idea of inclusion.

By way of conclusion: from momentary to the contextual understanding of reasonable accommodation

In the absence of any formal institutionalized generative supportive structures within the university spaces, support structures are provided within the informal care relations. These care relations are individualized momentary understanding of disability inclusion. As a generative process, reasonable accommodation should be contextually understood. The contextual articulations of reasonable accommodation will also provide space for subjective experiences of disability as well as the need for institutionalizing diverse needs coming from experiences that are diverse and multiple. But what we see currently is an ableist system build on exclusion, marking the burden of inclusion on individual bodies by completely erasing the contextual subjective experiences of the disabled. A reimagination of the process to understand the generative nature of reasonable accommodation is required to subvert the ideology of ableism.

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Jane Eyre's Angels: Disability, Gender, and Narrative Prosthesis in Brontë's Novel

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“You say you have faults, Helen: what are they? To me you seem very good,” the protagonist and namesake of *Jane Eyre* says to her friend Helen Burns.² Helen and Jane meet at Lowood boarding school and become fast friends. Jane admires Helen and is heartbroken when her illness worsens and she dies tragically. This paper will utilize Alison Kafer’s *Feminist, Queer, Crip* and Victorian writing to show how Brontë constructs Helen within two definitions of angelic personhood: first, the disabled “pillow angel” and second, the Victorian “angel in the house.” Next, it will examine how such roles are negative for Helen in the end because they reinforce each other, pigeonholing Helen into a position in which she is not only angelic, but also childish, which is a negative trait. It will then describe how this characterization restricts her to a life mediated by able-bodied people, and, if not for her premature death, by men. It will also show that the reinforcement between “pillow angel” and “angel in the house” is exemplified by the way her personality and fate differs from that of other disabled and female characters. Finally, it will demonstrate how this results in a novel in which disability is a limiting factor for women.

“Pillow angels” are people with severe mental and physical limitations who are “entirely dependent on their caregivers”; they are nicknamed as such by their caregivers because they lack the physical ability to move from the locations in which they are placed—usually a pillow.³ The category has a “slippery expansiveness”;⁴ in medical spheres, this expansiveness means that ableist procedures such as the Ashley Treatment can be applied to a wide variety of patients. The Ashley Treatment is named for Ashley X, a child with static encephalopathy whose mental development had stopped by age 6. Her parents approached her doctors with concerns about puberty and physical growth, and the doctors decided on a combination of hormone therapy for growth attenuation, mastectomy, and hysterectomy that is now known as the Ashley Treatment. Kafer’s analysis of the treatment reveals that it pathologizes the sexuality of Ashley as a disabled girl and future woman and utilizes fear of that sexuality to force her into perpetual childhood.⁵ In *Jane Eyre*, such slipperiness allows Helen to be categorized as a “pillow angel.”

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² Charlotte Brontë, *Jane Eyre* (New York: Warbler Press, 2020), 98.

³ Alison Kafer, *Feminist Queer Crip* (Bloomington: Indiana University Press, 2013), 53.

⁴ Kafer, 59.

⁵ *Ibid.*, 48.

Helen is portrayed as mentally sharp enlightened.⁶ However, Helen is severely ill, eventually bedridden with consumption that is ultimately fatal. She must rely on a teacher for her survival until her death.⁷ This leads to ableism as well, as Helen's portrayal as a pillow angel combines with her portrayal as an angel in the house to promote damaging stereotypes about both women and disabled people.

The idea of the Victorian "angel in the house" originated in a work of the same title by Coventry Patmore, which describes the ideal woman as a devoted and submissive wife who remained pure and dedicated to her husband, children, and faith. However, this image is contradictory. Patmore's ideas of women are upstanding, godly moral examples whose faith inspires those around them, but also as perpetual children, which reduces them to a flat, immature stereotype. Though unmarried, Helen fits this image perfectly. She submits without complaint to the unfair abuse of her teachers and believes that they are right about her faults.⁸ She is very religious, telling Jane, "make [Christ's] word your rule, and His conduct your example" and holds to this doctrine despite the poor treatment that she receives at Lowood, showing how religiously devoted she is.⁹ Her physicality is even directly called angelic; when she smiles, Jane comments that her smile is "like a reflection from the aspect of an angel".¹⁰ She is also literally a child, completely dependent on and trusting of the adults around her. Because she has a mindset that is not as mature as Jane's, she sees the adults in her life as always right and tries to please them.

Helen not only embodies both categories, but her characterization as an angel in the house also reinforces her characterization as a pillow angel, and vice versa. Helen is presented as better than both men and able-bodied people because of her angelic nature. This occurs before her illness, as described, and is further confirmed by Jane, who calls her "all I ever desire to be."¹¹ Jane serves as the novel's moral center, and because she sees Helen as an ethical example, the reader is meant to as well. However, the discovery that she is ill, and eventually terminal, makes her even more angelic, particularly from a religious point of view. Even on her deathbed, she demonstrates piety, saying, "I am sure there is a future state; I believe God is good,"¹² which shows her high level of devotion and purity untainted by suspicion. This utilizes the pillow

⁶ Brontë, 83.

⁷ Ibid, 125.

⁸ Ibid, 83.

⁹ Ibid, 86.

¹⁰ Ibid, 101.

¹¹ Ibid, 85.

¹² Brontë, 124.

angel model to reinforce the traits of the angel in the house archetype. The specific construct of her disability also contributes to her innocence, as it makes her blameless for her illness. In *Illness as Metaphor*, Susan Sontag writes that to be infected with or die from tuberculosis—the scientific name for Helen’s condition, consumption—was viewed as “a failure of will.”¹³ However, *Jane Eyre* emphasizes that Helen’s illness is due to “the combined injustices of patriarchy, class hierarchy, and social intolerance.”¹⁴ This provides Helen with a unique kind of innocence, first established by her angel in the house status and reinforced by her pillow angel characterization.

However, both of these positions mean that she is often presented as lower than both men and able-bodied people as well, specifically because she is childlike. Helen is inherently a young character and her youth becomes an excuse for her to be mistreated. Her disability adds another layer to her childlike nature and oppression. When she dies, she is small enough from her illness to fit in a crib, further playing into the trope raised by Kafer that connects disability with childhood.¹⁵ Additionally, this premature death makes her “frozen in time” just like Ashley X; neither will ever grow older or become sexually active.¹⁶ The Ashley Treatment was pioneered on Ashley to prevent “a grotesque, fertile body from coming into being.”¹⁷ The same tactic is at play in *Jane Eyre*. One of the primary ways in which women in *Jane Eyre* are assigned virtue are through lack of sexual activity unless they are monogamous, married adults; Jane is positively represented because she waits until marriage to have sex, and Celine Varens, the mother of Rochester’s child, was a sex worker and thus written about as lesser. Helen does not fit into either category. She was so young at the time of her death due to her disability that she never had a chance to make that choice and either become sexually active or not, meaning that she is perpetually virginal, innocent, childlike, and lower.

Finally, these two roles’ similarities lead to restricted experiences of the world for Helen. Both types of angel occupy spaces of dependency, domesticity, and passivity. Helen demonstrates this as a pillow angel; when her sickness worsens, she stops going to school and spending time with Jane. This withdrawal from life is prompted and controlled by able-bodied people. When Jane describes her disappearance, she says, “for some weeks she had been

¹³ Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors* (New York: Anchor Books, 1977), 63.

¹⁴ Susannah B. Mintz, “Illness, Disability, and Recognition in *Jane Eyre*,” in *The Madwoman and the Blindman: Jane Eyre, Discourse, Disability*, ed. David Bolt et al. (Columbus: Ohio State University Press, 2012), 132.

¹⁵ Brontë, 122.

¹⁶ Kafer, 66.

¹⁷ *Ibid*, 55.

removed from my sight,”¹⁸ which utilizes passive voice to imply that it was not Helen’s decision to stop seeing her friends. It was a decision made and imposed by able-bodied caretakers. Such measures of restriction and control continue during her exile. Her only contact with the outside world comes when she is “once or twice...taken by Miss Temple into the garden.”¹⁹ When she is provided infrequent access, it is prompted by her able-bodied caretaker. This, too, is demonstrated by the sentence’s content as well as syntax; Helen is the object of the sentence, not the subject. Readers can extrapolate from the other young women in the book that she would be similarly restrained as an angel in the house. Employment and marriage are women’s only two options in the novel, and both of those options provide little agency. This is especially true for women of lower socioeconomic status, as adult Helen would be. These women’s husbands, employers, or both control their movements and decisions, and would control Helen if she grew up.

In this text, able-bodied women are able to resist the angel in the house role to a degree. However, Helen is not because of the pillow angel role. This is clearest when examined in reference to Miss Temple and Jane. Miss Temple, the head teacher at Lowood, is kind, pious, and caring for the children at the school. These individuals greatly appreciate her, including Helen herself. However, despite the fact that Miss Temple fits many elements of the traditional angel in the house exactly, she is also able to redefine the role. For example, when Mr. Brocklehurst comes to the school, he accuses Jane of being a liar based on what he has heard from Mrs. Reed. Miss Temple challenges this by listening to Jane’s side of the story and then declares to the entire school that Jane is innocent, which directly contradicts a man in a way that the traditional angel in the house could never do.²⁰

Jane, similarly, is submissive to Mr. Rochester, first as his employee and then as his fiance. However, when Jane discovers that Mr. Rochester is still married to Bertha Mason, she stands up to him. He proposes, “You shall live a happy, and guarded, and most innocent life. Never fear that I wish to lure you into error—to make you my mistress” and Jane replies “If I lived with you as you desire, I should then be your mistress: to say otherwise is sophistical—is false.”²¹ She not only rejects this proposal but she also leaves her position as governess in his home. Like with Miss Temple, this resistance still exists in the same realm of traditional angelic

¹⁸ Brontë, 118.

¹⁹ Ibid, 119.

²⁰ Ibid, 111.

²¹ Brontë, 463.

womanhood. Jane refuses to go along with Rochester's plan because it exists outside of the realm of a conventional marriage, and this is unacceptable to her, which allows her to maintain her purity. However, it is also a type of resistance that other Victorian women in the house would not be allowed to have, as it prioritizes assertiveness, economic independence, and personal choice over marriage.

As shown, these women in the house redefine angelic womanhood. However, Helen is never allowed to show any kind of rebellious behavior. She is angelic to her last moment, and her reputation as an angel perseveres even when Helen is dead and physically removed from the narrative. By including this stark difference between Helen and other angel in the house characters, Brontë is making angelic womanhood a requirement for disabled women, but not for able-bodied women.

This is tied to the overall ableism displayed by Brontë's narrative; disabled characters are unable to falter from their original characterization, an element which is also demonstrated by the fact that Bertha Mason, despite her clear mental illness, is always demonized. She is quickly deteriorating to a state in which she is hurting others, escalating into the "madwoman" who attacks Mr. Mason, sets Mr. Rochester's bed on fire, and burns down all of Thornfield. Essentially, it is made clear that she is not an angel; even Jane's attempt to excuse her behavior—"she cannot help being mad"—is repeatedly countered by the tone with which she has described Bertha's actions.²² In literary criticism, her mental illness, described broadly as "madness," "has most frequently been seen as standing in for some other veiled or unspeakable condition" or "as an evocation of Jane's tightly constrained interiority or as the 'maddened double' of Brontë herself."²³

This is likely because Bertha's condition is mental rather than physical, a distinction that arises due to the literary traditions that associate sickness with romanticism and mental illness with terror. Sontag writes, "the dying tubercular is pictured as made more beautiful and more soulful" because it attacked the lungs, which were associated with life, and therefore viewed as a condition with spiritual meaning.²⁴ This can be seen in the description of Helen's end. When she is on her deathbed, Jane describes her as "so little changed" that Jane is no longer afraid to

²² Ibid, 459.

²³ David Bolt, "Introduction: The Madwoman and the Blindman," in *The Madwoman and the Blindman: Jane Eyre, Discourse, Disability*, ed. David Bolt et al (Columbus: Ohio State University Press, 2012), 3.

²⁴ Sontag, 17.

be near her, and her death serves to reemphasize her religious beliefs and even encourage Jane.²⁵ Those with mental illnesses, oppositely, are “strongly associated with violence, which they are perceived to generate from within themselves and to elicit from their surroundings.”²⁶ This legacy is reflected in *Jane Eyre*, as the majority of her interactions are violent. Even on a day when her caretaker describes her as “rather snappish, but not ‘rageous,’” her confrontation with Rochester is described as follows: “the lunatic sprang and grappled his throat viciously, and laid her teeth to his cheek.”²⁷ This violent illness makes her visibly different and makes her a worse, rather than better, person. The similarity between her and Helen is that both her villainization and Helen’s angelification are both permanent states.

This permanency also appears in regards to their sexuality. As mentioned, Helen’s disability traps her in a permanent state of childishness and virginity. Oppositely, Bertha is oversexualized. Many literary critics have hypothesized that Bertha’s “madness” is caused by syphilis, a sexually transmitted disease often associated with promiscuousness.²⁸ This condition is permanent and actively devolving. Additionally, both versions of sexuality are linked with illness and as a result, they are pathologized. In Bertha’s case, this pathologization serves as a reason for further ableist treatment from the characters around her. As Alexandra Nygren writes in “Disabled and Colonized: Bertha Mason in *Jane Eyre*,” Rochester “both excuses his own ill treatment of [Bertha] and shifts the ‘blame’ of disability onto Bertha herself by insinuating that she had contracted syphilis through lascivious behavior.”²⁹ This does not occur through Helen, whose physical disability manifests as childhood innocence and remains safe within her permanence in Victorian society, which was concerned with purity and eliminating sexuality. The dominant discourse was not opposed to her desexualization. Meanwhile, Bertha, as a sexually active woman with a sexually transmitted disease and a mental illness, is trapped at the intersection of two conditions that were looked down upon by Victorian society: active sexuality and “madness.” As a result, she is punished for existing permanently in this oversexualized state, even though it is not her fault, whereas Helen is not.

²⁵ Brontë, 122.

²⁶ Sylvia Huot, *Madness in Medieval French Literature: Identities Found and Lost* (Oxford: Oxford University Press, 2003), 65.

²⁷ Brontë, 447.

²⁸ Alexandra Nygren, “Disabled and Colonized: Bertha Mason in *Jane Eyre*,” *The Explicator* 74, no. 2 (2016): 117.

²⁹ Nygren, 118.

Both types of permanency starkly contrast with Rochester. Rochester's status as able-bodied is "neither permanent nor impermeable."³⁰ He begins the narrative as completely able-bodied, but later, he becomes disabled: "one eye was knocked out, and one hand so crushed that Mr. Carter, the surgeon, had to amputate it directly. The other eye inflamed: he lost sight of that also. He is now helpless, indeed—blind and a cripple."³¹ Jane marries Rochester regardless and serves as his caretaker. Rochester remains "a cripple," missing one hand and one eye, but several years into their marriage, Rochester informs Jane that he believes his sight is returning to his remaining eye. He still remains disabled, but his condition is not permanently deteriorating. He is able to participate in elements of regular life and is not relegated to an existence tempered by able-bodied people. Like with Helen, this is exemplified both through content and syntax. When Jane first goes to see him again, when he is fully blind, he is still the subject of a plethora of verbs.³² He remains completely in control of his own experience, even when disabled, unlike Helen or Bertha.

His characterization is also fluid. Rochester acts rudely, manipulatively, and cruelly toward Jane throughout their relationship. Even when he and Jane are engaged and she does know that he cares about her, he still does not treat her kindly. However, Jane's absence causes him a change of heart. When they reunite, the dynamic between the two has completely shifted, both in terms of his language and his actions toward Jane, and their relationship from then on follows this pattern. Jane refers to their marriage as "perfect concord" as she reflects on it near the novel's end.³³ Character growth like Rochester shows is a privilege that is not granted to Helen or Bertha because of their disabled statuses.

Rochester is also mobile sexually. He marries Bertha, but when he realizes that she is mentally ill and in decline, he decides to seek pleasure elsewhere. He travels the world and has sexual relationships with women in Italy, Germany, and France. However, when discussing the topic with Jane on their wedding day, he says "I now hate the recollection of the time I passed" with those mistresses and states that he has not had extramarital sex since, demonstrating that he is able to move between the state of sexual activity and the state of sexual inactivity.³⁴ Even when he proposes to Jane that they live together without being married, navigating around his marriage to Bertha, he attempts to reassure Jane by telling her, "Never fear that I wish...to make

³⁰ Kafer, 25.

³¹ Brontë, 655.

³² *Ibid.*, 660-661.

³³ Brontë, 688.

³⁴ *Ibid.*, 475.

you my mistress.”³⁵ This demonstrates again that he is now able to exist in the non-sexually-active role even when he returns somewhat to his former patterns. Lastly, Jane reveals that he does eventually return to sexual activity; the two have a child together.³⁶ Additionally, neither of Rochester’s sexual expressions are pathologized. His sexual activity is morally corrupt when it occurs outside of marriage, but it is a moral failing, not a medical problem, and his sexual activity within marriage and sexual abstinence outside of marriage are presented as natural.

This difference in portrayal is due to narrative prosthesis. This term is defined as the idea that narratives rely on disability to “lend a distinctive idiosyncrasy to any character that differentiates the character from the anonymous background of the ‘norm.’”³⁷ This perfectly describes the reasons for Helen, Bertha, and Rochester’s characterizations. Helen needs to stand out as a perfect angel to inspire Jane; Bertha needs to stand out as a villain to stand as an obstacle to Jane and prompt Jane and Rochester’s character development. Rochester, oppositely, does not need disability to differentiate him. Rochester is already different from the norm because he provides a place for Jane where she consistently feels at home, and she finds him interesting and intellectual. She is already romantically attracted to him before he becomes disabled and remains so as his disability shifts, so his disability does not serve the cause of narrative prosthesis unlike Helen and Bertha’s disabilities do.

Disability often also serves the purpose of metaphor in literature because aligning a physical body with a metaphorical belief “offers representational literatures a way of grasping that which is most unavailable to them.”³⁸ This lens shows that the disabled characters in this narrative only exist as tools for the able-bodied characters to grasp at ideas about morality, religion, and sexuality. Helen’s angelic nature is an example for Jane, and Bertha’s demonic nature is a warning, but Jane is always able-bodied, meaning that these disabled characters are always serving her. Rochester only knows Bertha, but his interactions with her follow a similar pattern. Meanwhile, these traits actively suppress Helen and Bertha. This is ableist and reductive. While outside of the scope of this paper, *Jane Eyre* also falls into a greater pattern of female disabled characters in the nineteenth-century British novel and a cultural context of real-

³⁵ Ibid, 463.

³⁶ Ibid, 689.

³⁷ David T. Mitchell and Sharon L. Snyder, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (Ann Arbor: The University of Michigan Press, 2000), 47.

³⁸ Mitchell and Snyder, 63.

world ableism. Overall, *Jane Eyre* promotes an ableist narrative that is a literary and practical issue.

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**The problem with empathy in narrating children's disability: Ableist discourses in
Dickens' *A Christmas Carol* and *Nicholas Nickleby***

Enrica Zaninotto¹

As a chronically-ill disabled person, I vividly remember how, throughout my entire childhood, adults used to treat me as a “frightened, shy little thing”². With little or no awareness at all of what Ableism, as well as internalized Ableism, were, I grew up misconceiving myself as a pitiful creature who needed nothing but protection, compassion and isolation. As years passed, I soon got used to sympathetic attitudes aimed at empathising with my non-able-bodied nature. Nonetheless, due to the lack of disabled representation among my peers during primary and middle school years, I ended up persuading myself it was, in the end, normal: to be treated as an outcast, to be touched by strangers without explicit consent, to be addressed to as a hopeless child forced to live a miserable existence. Still, it took me two decades to acknowledge that not only were my self-value and self-concept based on false assumptions shaped by our ableist society, but also that all those unpleasant attitudes brought into action by non-disabled people were provoked by a hidden attraction towards my unknown disablement. Therefore, not coincidentally, it has been proved that “disgust or repulsion masks a secret attraction to the object; so too must one analyse the negative feelings associated with disability. The common response of normal people is to say that the disabled object produces strong feelings ranging from disgust to pity in the observer”³. Taking into account the post-post-modern narrative according to which disability can be understood as a partial social construction, then, it is easier to comprehend how able-bodied, while consciously noticing disabled people because of their clear physical malformations, are hardly ever capable of identifying the negative outcomes related to their unconscious, if not uncanny, judgements⁴. Thus, people whose bodies conform within the stereotypical canons of normalcy mask their suppressed curiosity for impaired subjects with feelings of mercy and insincere empathy. In such a mental framework, indeed, realising that disability is not an absolute, but instead a fluid category, and consequently admitting that the condition of being abled-bodied is only temporary, appears way too worrisome and unsettling.

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² Brontë Charlotte, *Jane Eyre* (Ware: Wordsworth Editions, 1999), 32.

³ Davis J. Lennard, *Enforcing Normalcy. Disability, Deafness, and the Body* (New York: Verso, 1995), 12.

⁴ Siebers Tobin, “Disability in Theory: From Social Constructionism to the New Realism of the Body”, *American Literary History* 13, no. 4 (2001): 739.

Broadly speaking, hence, we cannot have a discussion about ableist behaviours carried out towards disabled people without considering the significant role that empathy plays in this respect. As a matter of fact, if, as already suggested, children affected by either physical, sensory or intellectual disabilities are treated as unprotected human beings, destined to be seen and (mis)valued only because of their abnormal condition, such process of systematic stigmatisation is even strengthened when they turn into adults. It is no surprise, then, that the great majority of disabled men and women experience, during their adulthood, the same subtle discriminations they were subjected to when they were children. As a result, from this point of view, analysing the key function of empathy in the perpetuation of ableist discourses related to disabled children becomes essential in order to throw new light on this rarely-analysed topic. Therefore, since literature is, in the majority of cases, a mirror of life itself, the same ableist dichotomies of sympathy at work in society can be observed translated in literary texts. During the last two decades critics have in fact noticed some “recurring stereotypes perpetuated by literary texts and argue that archetypal disability narratives are often misrepresentations which fail to do justice to the complexities of disability as an identity”⁵. More specifically in the Victorian novel, unconsciously intended by nineteenth-century writers as a conservative archetype, we encounter the best and most stereotypical depiction of disability. Impaired nineteenth-century characters serve as a mere tool introduced in the narrative in order to reinforce the commonly-accepted vision of the normal body, while simultaneously embodying deviance and disturbance.

In such a dysfunctional narration, among Victorian novelists, Charles Dickens, in his vast literary production, offers us countless possibilities to analyse and detect diverse depictions of the normal and the deviant. At the same time, such vast inclusion of disabled characters, marked by different medical conditions ranging from epilepsy to physical deformities, testifies Dickens’ complete immersion in the typically-Victorian kind of consciousness obsessed with the human body, indicating that his novels are a clear product of his time. It is no coincidence indeed that, aligning with nineteenth-century narrative strategies concerned with the rendering of impairments, he frequently introduces disabled subjects so as to give more importance to some characteristic *leitmotifs* of his work. In so doing, the reader can thus come across portrayals of non-able-bodied figures starting from his earlier novels, namely, among others, *Oliver Twist* (1838), *Nicholas Nickleby* (1839), *The Old Curiosity Shop* (1840) and *Barnaby*

⁵ Hall Alice, *Literature and Disability* (Abingdon: Routledge, 2016), 32.

Rudge (1841), as well as in later literary works such as *Hard Times* (1854), *Little Dorrit* (1857) and *Our Mutual Friend* (1865). As a consequence, it would be no exaggeration to affirm that disability somehow functions as a *fil rouge* in the Dickensian scenario. Nonetheless, assuming that all these disabled characters share the same features and are represented according to the same socio-psychological dynamics would be rather incorrect. In general terms, we can agree in saying that Dickens, in the process of creation of impaired subjects, focuses his attention mainly on the surrounding scene rather than on the characters themselves. For this reason, it goes without saying that, in the systematised means of composition of disability, the author highlights more the spectator's point of view rather than that of the non-able-bodied being looked at. By making the description of the disabled revolve around the observer, the emotions produced upon the able-bodied by the act of gazing will therefore be emphasised. Not coincidentally, this is what happens in most Dickensian disabled narratives. Still, it is in this sentimental objectification of the abnormal that we find an ambivalent portrait of disability, which has to be interpreted both as a binary opposition, as well as an ascending trend. As a matter of fact, in Dickens' fictional universe, two distinct versions of the non-able-bodied are possible: on the one hand, they can either be angel-like reassuring figures, as it is the case with the pitiable Tiny Tim in *A Christmas Carol* (1843), or on the other devilish and immoral characters who can be gathered under the label of "demonic cripples"⁶. Nonetheless, the socio-psychological implications of Dickensian disabled representation, as well as misrepresentation, go beyond such distinction, giving birth to a way more intrigued general image. Accordingly, first of all it is crucial to point out that not only is Dickens' ethic perception of the disabled mediated and modelled by his lack of self-awareness of what being disabled means, but also that his narrative viewpoint appears, to some degree, variable and, at the same time, predictable. It has been observed, in fact, that Dickens' own understanding of the disabled person changes with time and according to his own personal intentions, resulting in a rather intricate portrayal. In this respect, Julia Melie Rodas explains that:

Dickens begins with a rather simplistic approach to disability, seizing upon it and attempting to bend it to his purposes as a writer (using disability as a tool of affect/sentimentality), but as the disabled figures about whom he writes begin to exert an unexpected agency, Dickens's approach to disabled identity shifts growing more complex and more troubled. I argue here that Dickens' functions as a satellite to disability, that he is drawn to the implicit power and authenticity of

⁶ Wainapel F. Stanley, "Dickens and disability", *Disability and rehabilitation* 18, no. 12 (1996): 629.

the disabled subject (...) – motivated in part by the desire to construct himself as a beneficent mediating agent, in part by an unconscious wish to assert his own normative identity.⁷

Still, from an initial subjective and selfish depiction of the disabled other, Dickens moves toward what I would define as a more contemporary way of narrating and shaping disabled characters who, in the end, start speaking their own voice, distancing from the one of their creator. Nevertheless, such final rejection of subjectivity on the part of the novelist has to be intended only as the ending point, which develops in opposition to his earliest conception of the non-able-bodied in scientific and sentimental terms. Indeed, Dickens' emotional involvement in the act of constructing his impaired characters is clearly testified by the declaration of the feelings experienced while writing *A Christmas Carol*, and more specifically about Tiny Tim: according to his biographer Edgar Johnson, the Victorian novelist “wept and laughed, and wept again, and excited himself in a most extraordinary manner”⁸. This observation on the part of Dickens does nothing but mirror the pitiable depiction of Tiny Tim, while simultaneously further perpetuating the stereotypical image of the disabled child as hopeless and pathetic. In the Christmas book, indeed, Dickens seems to strengthen ableist discourses related to impaired children, showing how his agreement to the normative canon is both a logical outcome of his own Ableism, as well as a typical key-concept of Victorian psychology. Not surprisingly, “Tim seems as limited by Victorian notions of disabled children as he is by his physical limitations”⁹.

Depicted as a “patient and mild (...) little, little child”¹⁰ with a “plaintive little voice”¹¹, from the beginning Tim Cratchit is generally known as *Tiny Tim*, thus insisting on the conventional iconography which culturally depicts disabled children as miserable defenceless creatures. Hence, in such a fictional scenario, *Tiny Tim* appears to be a pathos-inspiring symbol of the working-class rather than an actual character, a source of spectacle instead of an active agent. Nevertheless, the author provides no medical account nor detailed prognosis related to his abnormal condition: hints of his fragility are given in state three when Scrooge asks: “Spirit

⁷ Rodas Julia Miele, “Tiny Tim, Blind Bertha, and the Resistance of Miss Mowcher: Charles Dickens and the Uses of Disability”, *Dickens Studies Annual* 34 (2004): 52.

⁸ Holmes Stoddard Martha, *Fictions of Affliction: Physical Disability in Victorian Culture* (Ann Arbor: University of Michigan Press, 2009), 95.

⁹ Kanwit John Paul M., “People muht be amuthed”: Work, Play, and the Dickensian Disabled Child”, *Dickens Studies Annual* 47 (2016): 39.

¹⁰ Dickens Charles, *A Christmas Carol* (Ware: Wordsworth Editions Limited, 2018), 83.

¹¹ Dickens Charles, *A Christmas Carol* (Ware: Wordsworth Editions Limited, 2018), 60.

(...) tell me if Tiny Tim will live”¹², reinforcing damaging clichés describing the disabled child as destined to die young because of his illness.

Likewise, the painting of the deviant recurs in the episode narrating Tim’s visit to the church on Christmas day. The narrator, in fact, explicitly identifies *Tiny* Tim as a public pitiful freak of nature, emphasising how he enjoys being looked at because of his impairment and thus, in a way, possibly anticipating of Freud’s view of disability, as well as the reactions it arises in non-disabled people. As a matter of fact, in a conversation between Bob Cratchit and Mrs Cratchit, we read:

“And how did little Tim behave?” asked Mrs. Cratchit (...) “As good as gold,” said Bob, “and better. Somehow, he gets thoughtful, sitting by himself so much, and thinks the strangest things you ever heard. He told me, coming home, that he hoped the people saw him in the church, because he was a cripple, and it might be pleasant to them to remember upon Christmas Day who made lame beggars walk and blind men see.” Bob’s voice was tremulous when he told them this, and trembled more when he said that Tiny Tim was growing strong and hearty.¹³

Therefore, *Tiny* Tim finds pleasure both in being glanced at because of his disability, as well as in the very act of admiring non-able-bodied in his turn. In this dynamic of gazes, we can detect Dickens’ own reflection of his hidden attraction for disabled subjects, while not being able to recognise the feelings of compassion and disgust provoked by the deviant.

Generally speaking, according to what has been previously discussed, there is no doubt that the characterisation of Tim Cratchit, marked by several disadvantageous qualifiers which overall identify him as an afflicted child who personifies emotional excesses, results in the miserable social portrait of children’s disability that disability rights activists nowadays repudiate and fight. Ergo, as demonstrated, we can notice that, firstly, Dickens’ use of empathy and compassion mirrors his interiorised Ableism and, secondly, that such sympathetic attitudes are still applied today when interacting with impaired children in the same way they were employed throughout the nineteenth century. What is more, such pitiable way of behaving towards young disabled boys does not only distinguish *A Christmas Carol*, but it instead can be found also in other Dickensian literary productions, namely *Nicholas Nickleby*. This novel, indeed, despite not revolving around impairments at all, offers us another possibility

¹² Dickens Charles, *A Christmas Carol* (Ware: Wordsworth Editions Limited, 2018), 58.

¹³ Charles, *A Christmas Carol*, 54.

to prove the initial statement of this research: Dickens' way of rendering children's disability is deeply intertwined with questions of pity and consequent systematic Ableism still widely widespread in our present society. As it happened in the Christmas book, in fact, the novelist makes use of negative adjectives so as to sympathetically characterise impaired children. In this case Smike's misery, along with the one of his mates at Dotheboys Hall (an institution for physically-disabled boys), becomes apparent in chapter eight:

Pale and haggard faces, lank and bony figures, children with the countenances of old men, deformities with irons upon their limbs, boys of stunted growth, and others whose long meagre legs would hardly bear their stooping bodies, all crowded on the view together; there were the bleared eye, the hare-lip, the crooked foot, and every ugliness or distortion that told of unnatural aversion conceived by parents for their offspring, or of young lives which, from the earliest dawn of infancy, had been one horrible endurance of cruelty and neglect. There were little faces which should have been handsome, darkened with the scowl of sullen, dogged suffering; there was childhood with the light of its eye quenched, its beauty gone, and its helplessness alone remaining.¹⁴

Depicted as a lame young boy, Smike's disablement, as much as *Tiny Tim's*, resists medical characterisation: the reader is not allowed to know whether he has a physical, sensory or intellectual disability. Nonetheless, Dickens applies the same kind of methodical use of adjectives aimed at melodramatically portray the non-able-bodied. As a matter of fact, Smike is, as much as Tim Cratchit, a "timid, broken-spirited creature."¹⁵ In addition, Smike's overall depiction appears, in the end, even more dramatic: due to his abnormal body, he is portrayed as the deviant other of Nicholas, who can hardly ever become successful in a working environment without depending on the able-bodied.

In conclusion, we can agree in affirming that these two young disabled characters function, above all, as objects of sympathy in a cyclic sentimental economy which perpetuates ableist behaviours carried out by non-impaired people. The narrative depiction of disabled children as charitable weak subjects arousing pity in the able-bodied adult spectator, then, works as a reflection of shared social and psychological attitudes grounded on Ableism. It follows, then, that if at first the empathy felt on the part of the able-bodied (in this case, the narrator) towards the deviant child can appear profitable and welcomed, it ends up doing

¹⁴ Dickens Charles, *Nicholas Nickleby* (Ware: Wordsworth Editions Limited, 2000), 89.

¹⁵ Charles, *Nicholas Nickleby*, 97.

nothing but watering the seeds of systematic acts of discrimination. As a result, according to what has been discussed, from the perspective of a post-post-modern scholar who is well aware of the multiple ways in which Ableism affects the daily life of disabled people of all ages, I argue that we can use nineteenth century impaired-related narratives in order to study, and therefore demonstrate, how stigma and injustice towards disabled children are rooted in our civilization. It is only by acknowledging them, in fact, that we can fight them systematically.

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Blindness and the Beast: Disability and Fairy Tale in Wilkie Collins' *Poor Miss Finch*

György Kiss¹

If one is researching disabled identities and physical anomalies in Victorian fiction, Wilkie Collins is a source quite unparalleled: the majority of his novels feature at least one character who is disabled or disfigured. In his biography of Collins, Peter Ackroyd writes, “in his published work he often draws attention to physical abnormalities that give a clue to distinctive character, [...] he also mentions among other ailments epilepsy, spinal defects, facial deformities, and paralysis of the limbs.”² Ackroyd connects Collins’ lifelong literary interest of physical Otherness to the author’s unusual appearance and bodily afflictions. Not only was Collins’ “head too large for his body; his arms and his legs too short, while his hands and feet were too small,”³ he was a chronic sufferer of rheumatic gout as well. In more ways than one, these illnesses and deformities all can be found in the pages of Collins’ works, but as I see it, no other novel mirrors his real-life experience more than *Poor Miss Finch*, which revolves around blindness. In her introduction to the novel, Catherine Peters claims that Collins “suffered himself from lifelong short sight, and also from a disease which caused both severe arthritis and recurrent inflammation of the eyes, which was painfully affecting them at the time he was writing *Poor Miss Finch*.”⁴ This (nowadays quite neglected and overlooked) novel was published in 1872 and uses blindness as its central theme. Losing one’s sight is a topic not uncommon to the literature of the Victorian era; however, the majority of novels that feature blindness incorporate this notion into an overarching theme that often moves away from the faithful portrayal of disability and address contemporary social issues instead. For example, Bertha Plummer’s physical blindness in Dickens’ *The Cricket on the Heart* (1845) is secondary to her blind unconsciousness of (proper) social roles for girls and women. By the end of the short story, she “learns” to see how to behave as her position requires her to, but never regains her real sight. *Poor Miss Finch* offers a more complex narrative in which blindness functions on several levels. The novel remains one of the few Victorian works that explore the notion of blindness not only as a metaphor, but a medical condition as well, while also taking account of the psychological implications and effects of visual impairment. In my paper, I argue that the multi-layered exploration of blindness (and disability) in *Poor Miss Finch* is achieved through

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² Peter Ackroyd, *Wilkie Collins* (London: Vintage Books, 2013), 1.

³ Ackroyd, 1.

⁴ Wilkie Collins, *Poor Miss Finch*, int. by Catherine Peters (Oxford: Oxford University Press, 2000), x.

the use of myth and fairy tale, namely the ancient ‘Cupid and Psyche’ myth and the tale of ‘Beauty and the Beast’.

Collins’ decision to draw inspiration from the fairy tale world is quite plausible, for in its core, the genre is strongly connected to disability. According to David T. Mitchell and Sharon L. Snyder:

The very need for a story is called into being when something has gone amiss with the known world. [...] Since what we now call disability has been historically narrated as that which characterizes a body as deviant from shared norms of bodily appearance and ability, disability has functioned throughout history as one of the most marked and remarked on differences that propel the act of storytelling into existence.⁵

Stories like Andersen’s ‘Thumbelina’ (1835), ‘The Girl Who Trod on a Loaf’ (1859), or the Grimm Brothers’ ‘The Maiden Without Hands’ (1812), and ‘One Eye, Two Eyes, Three Eyes’ (1815), are just a few examples of the many fables that operate with physically disfigured main characters. ‘Beauty and the Beast’, one of the most beloved and well-known fairy tales today, uses the same pattern with its enchanted prince who is forced to live a secluded life, cursed with a monstrous figure. As fairy stories go, ‘Beauty and the Beast’ has many origins and variations all over the globe, as anticipated, yet in Western culture the most prevalent version is Gabrielle-Suzanne Barbot de Villeneuve’s 1740 rendition, largely based on the Roman myth of Cupid and Psyche. This tale is part of a bigger narrative by Apuleius, titled *The Golden Ass* (sometimes titled or translated as *Metamorphoses*), which was written in the 2nd century CE. The myth features Psyche, who marries the god Cupid; however, he remains invisible to her throughout their marriage. E. J. Kenney writes, “through the tale of Cupid and Psyche [...] Apuleius’ book has exerted its greatest influence. The story has been a perennial source of inspiration to poets, dramatists, composers for opera and ballet, and artists,”⁶ and Collins is no exception. In *Poor Miss Finch*, we follow the life of a young blind woman, Lucilla Finch, who falls in love with a man named Oscar Dubourg, whose appearance can be described as monster-like. The fact that Lucilla cannot see Oscar (and knows nothing about his Otherness) conjures up both ‘Beauty and the Beast’ and ‘Cupid and Psyche’, thus providing a mythical, fairy tale framework to the novel. Although the plot evokes these familiar tales, Collins incorporates and rethinks many of their elements to fit them into the 19th-century genre of the realist novel and provide a sensible

⁵ David T. Mitchell and Sharon L. Snyder, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (Ann Arbor: University of Michigan Press, 2000), 53-4.

⁶ Apuleius, *The Golden Ass*, int. and trans. by E. J. Kenney (New York: Penguin Classics, 2004), Introduction, Kindle.

approach. As Hilary Newman suggests, “Collins’s novels delight, but they also disguise their subversive ideas on disability by smuggling them in under fairy-tale plots and character elements.”⁷ Ultimately, *Poor Miss Finch* is a novel about Otherness, let this be physical, social, or mental divergence from the norm. However, it is through the figures of Lucilla and Oscar that fairy tale, myth, and disability is mainly explored: “the plot of *Poor Miss Finch* focuses on two bodies, each notably marked: the blue Oscar and the blind Lucilla.”⁸ In the next part of my essay, I am analysing these two characters in relation to their mythological counterparts and physical Otherness.

The myth of Cupid and Psyche is essentially about curiosity: Psyche wants to see the concealed husband she was forced to wed. They are united in the dark bedroom only, where their way of communicating is through talking and touching. Apuleius’ line, “that night her husband spoke to Psyche – for though she could not see him, her hands and ears told her that he was there,”⁹ could easily be read as an experience of Lucilla’s: similarly to Psyche, she cannot see her husband-to-be Oscar. It takes time for Psyche to warm to her invisible partner, but Collins assures the reader of Lucilla’s confidence in her blindness from the first moment: “instead of her blindness making her nervous in the presence of a man unknown to her, it appeared to have exactly the contrary effect. It made her fearless.”¹⁰ Although akin to Psyche in considerable detail, Lucilla shows great deal of independence. Knowing her way in the dark, she scorns the friend who offers to navigate her: “My dear Madame Pratulungo! I know my way better than you do. I roam all over the neighborhood, with nothing to help me but this [my walking-cane].”¹¹ Psyche’s and Lucilla’s curiosity and desire of seeing their lover remain unknown to them as long as they believe there is no way of erasing the darkness from their lives. In both instances, the changing force is external: Psyche is convinced by her sisters to glance at her husband by lighting a candle, and Lucilla is prompted to undergo a cataract surgery to restore her vision by her eye-doctor, which she accepts only to see Oscar. Psyche is posed as a passive agent whose first act of autonomy (peeking at her husband through the light of the candle) becomes her hubris that leads to her downfall and the loss of her beloved. Cupid is

⁷ Hilary Newman, “John Kitto's The Lost Senses: Deafness and Blindness and Wilkie Collins's *Hide and Seek* and *Poor Miss Finch*,” *The Wilkie Collins Journal*, vol. 12 (2013), accessed February 27, 2022, <https://wilkiecollinsociety.org/john-kittos-the-lost-senses-deafness-and-blindness-and-wilkie-collins-hide-and-peek-and-poor-miss-finch/>.

⁸ Samuel Lyndon Gladden, “Spectacular Deceptions: Closets, Secrets, and Identity in Wilkie Collins's *Poor Miss Finch*,” *Victorian Literature and Culture*, vol. 33, no. 2 (2005): 470, JSTOR, accessed February 27, 2022, <https://www.jstor.org/stable/25058724>.

⁹ Apuleius, Book Five.

¹⁰ Collins, 37.

¹¹ Collins, 18.

injured by the wax of the candle and flees; so does Oscar when Lucilla is able to see again, for he fears Lucilla would not love her with his grotesque appearance he kept a secret. Consequently, Lucilla unwittingly creates her own misery with the operation of her eyes.

Just like Lucilla, Psyche is blind to her lover's true personality and origins. Yet at this part, *Poor Miss Finch* notably differs from the myth. One can hardly read Oscar as Cupid-like godly being. True, he *is* otherworldly, but in the negative sense of the word: he is the feared and beastly image of a husband imagined by Psyche's sisters. However, Oscar is not monstrous in the traditional fairy-tale logic, instead his inner turmoil (his mental weakness, femininity, criminal background and possible queerness) are manifested on his body in the form of epilepsy and discoloured skin: "The man's face, instead of exhibiting any of the usual shades of complexion, was hideously distinguished by a superhuman – I had almost said a devilish – colouring of livid blackish blue!"¹² In Apuleius' myth, the goddess Venus plans to punish Psyche in the following way: "let this girl be seized with a burning passion for the lowest of mankind, some creature cursed by Fortune in rank, in estate, in condition, someone so degraded that in all the world he can find no wretchedness to equal his own."¹³ Is Lucilla the true sufferer of this punishment, even though she is not aware of it? Oscar is transformed into an Other, a figure in Victorian literature that is often hidden from (public) view, and one that needs to hide from Lucilla not to become the object of her disgust: "the visibly disabled body intrudes on our routine visual landscape [...] often obscuring the personhood of its bearer"¹⁴, writes Rosemarie Garland-Thomson. In Collins' novel, one of Lucilla's recurring identifying traits is her aversion to dark colours she can magically feel but cannot see: "She has a positively painful association with dark colors, on certain occasions. They sometimes produce a disagreeable impression on her nerves, through her sense of touch."¹⁵ As Lucilla claims, "I have my own blind horror of anything that is dark."¹⁶ The dichotomy of darkness and light runs throughout *Poor Miss Finch*, mostly paralleled in the figures of Lucilla and Oscar. With her purity and love, Lucilla represents light in spite of living in her dark world (her name also comes from the Latin word "lux" meaning "light"), whereas the dark-skinned, depressive Oscar is able to see the light of the physical world that Lucilla cannot, and resents it because of his own image.

¹² Collins, 105.

¹³ Apuleius, Book Four.

¹⁴ Rosemarie Garland-Thomson, *Staring: How we look* (New York: Oxford University Press, 2009), 20.

¹⁵ Collins, 152.

¹⁶ Collins, 14.

Psyche's and Lucilla's quest for Love begins as soon as they lose their partner. Nevertheless, their journey is anything but traditionally heroic: Psyche becomes "overwhelmed completely by the weight of dangers she was powerless to cope with,"¹⁷ and Lucilla loses the confidence she possessed earlier as a blind woman. After her surgery, she is instructed to rest her eyes avoid any mental disturbance; but, similarly to her mythical counterpart, cannot feel at ease when she believes her love life and happiness to be at peril. As a result, she loses her vision again: "the mischief done to her eyes by her reckless use of them, by her fits of crying, by her disturbed nights, by the long-continued strain on her of agitation and suspense, has evidently justified the worst of those unacknowledged forebodings which Grosse [her doctor] felt when he saw her."¹⁸ Lucilla is rejoined with Oscar only after she goes blind for the second time, achieving their "happily ever after" ending so. Ann Schmiesing writes, "when a disabled hero is portrayed, his heroic qualities are often brought to the fore as he triumphs despite the social stigma of his disability – a triumph typically rewarded in fairy tales with the magical erasure of his physical anomaly."¹⁹ Although there is no symbolic scene of transformation from Beast to Prince in *Poor Miss Finch*, in his own, quiet way, Oscar does triumph in the end and is rewarded accordingly. His newfound boldness helps him cope with his disfigurement. He comes clean to Lucilla, who welcomes his affections in spite of his (inner and outer) darkness. To reach such a conclusion, Lucilla indeed has to lose her sight, otherwise her romance with Oscar would not be possible: "Do you think I wish to see him disfigured as he is now? No! I wish to see him – and I do see him! – as my fancy drew his picture in the first days of our love,"²⁰ she admits. The last words she speaks in the novel are, "My blindness is my blessing," and "My life lives in my love. And my love lives in my blindness"²¹ Thus Cupid and Psyche are reunited again.

Reading Lucilla's proclamation, a question arises: is this the moral of Collins' fairy tale? In order to understand the message of *Poor Miss Finch*, one needs to go back to its origins yet again. Bruno Bettelheim's Freudian reading of 'Beauty and the Beast'; "the girl can transfer – and transform – this oedipal love for her father most freely and happily to her lover,"²² is hardly applicable to the novel considering Lucilla's personal relationship with his father is nearly non-existent. On the other hand, it would be deficient to state that *Poor Miss Finch* was written only

¹⁷ Apuleius, Book Six.

¹⁸ Collins, 374.

¹⁹ Ann Schmiesing, *Disability, Deformity, and Disease in the Grimms' Fairy Tales* (Detroit: Wayne State University Press, 2014), 2.

²⁰ Collins, 418.

²¹ Collins, 418.

²² Bruno Bettelheim, *The Uses of Enchantment: The Meaning and Importance of Fairy Tales* (New York: Vintage, 2010), *The Animal-Groom Cycle of Fairy Tales*, Kindle.

to support the age-old belief of beauty lying within. Collins was more likely motivated by the morals of 'Cupid and Psyche', creating a parable of his own that partially rewrites the teachings of the ancient myth. To quote Kenney, 'Cupid and Psyche' is "thematically the story of a, or rather the, human soul in quest of salvation through union with the divine."²³ *Poor Miss Finch*, although occasionally evoking religious imaginary, remains a non-spiritual work, "salvation" and "union with the divine" therefore translate to human experiences in the "real" world. As I observe above, Psyche's hubris is her curiosity that resonates with Lucilla's wish: what would it be like to see? By the end of their stories, both learn the error of their ways, but Lucilla's case is rather exceptional; for she, unlike Psyche, stays in the dark, yet becomes content with her situation. Following this logic, the ultimate message of *Poor Miss Finch* is acceptance and love: not only for the Beast, but for oneself as a blind woman. As Martha Stoddard Holmes phrases it, the novel's "core narrative of a blind woman falling in love, marrying, and having children – without first being 'cured' – remains a rarity in fiction and film."²⁴ Through experiencing life both as a seeing and unseeing individual, Lucilla understands where her true nature lies and achieves salvation as a disabled person by the end of the novel. In *Poor Miss Finch*, the personal, medical, symbolic and psychological approaches towards disability artlessly merge together in a foundation based on myth and fairy tale. As a closing quote of my essay, I am referring to Newman, who writes, "while wishing to educate, Collins had no intention of writing a dry scientific treatise on disability. Therefore, he chose to combine realism and romance, according to the classical Horatian formula of bestowing both profit and pleasure."²⁵ Realism is not the opposite of myth: *Poor Miss Finch* is the proof of that.

²³ Apuleius, Introduction.

²⁴ Martha Stoddard Holmes, *Fictions of Affliction: Physical Disability in Victorian Culture* (Ann Arbor: University of Michigan, 2009), 60.

²⁵ Newman, "John Kitto's The Lost Senses."

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“She was dainty and fair to see, but she was no taller than your thumb. So she was called Thumbelina”: Gender, Disability, and Visual Forms in Hans Christian Andersen’s ‘Thumbelina’ (1835)

Hannah Helm¹

This paper explores representations of femininity and disability in literary and artistic variants of Hans Christian Andersen’s fairy tale ‘Thumbelina’ (1835). I argue that although Andersen in part upholds gendered and ableist norms, the literary tale, illustrations, and Andersen’s own paper art also query nineteenth-century beliefs about femininity and the normative body. By offering some exploratory insights about gender and disability in the ‘Thumbelina’ fairy tale and its associated visual forms, I build on Emily Hayden’s recent argument that ‘children’s literature has emerged as a particularly compelling tool for forming narratives that push back against societal tropes.’²

In this paper, I engage with the key disability concept of ‘access’. According to disability scholar Bess Williamson, the term ‘has been used to characterize the relationship between the disabled body and the physical environment’.³ Furthermore, Williamson states that ‘[i]n its most literal form, “access” describes the ability to enter into, move about within, and operate the facilities of a site’.⁴ In Andersen’s tale, Thumbelina’s physical smallness means that she must navigate an inhospitable physical environment that accommodates only particular types of bodies; Thumbelina ‘is so small and light that [the environment is] just like an island to her’.⁵ The character conforms to normative standards of appearance and physical ability, but she is deemed non-normative in the social world presented by the tale, which means that her character can be read through a Disability Studies framework. As Rachel Adams suggests: ‘disability itself always begins and ends with the subjective impressions of the individual who experiences the world through her body’.⁶ Thumbelina’s smallness enables other characters to manipulate and physically control her body, and disability scholar Nick Watson argues that ‘the common

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² Emily Hayden, “Disrupting Ableism: Strength-based Representations of Disability in Children’s Picture Books”, *Journal of Early Childhood Literacy* 20, no. 4 (2020): 2.

³ Bess Williamson, “Access”, in *Keywords for Disability Studies*, eds. Benjamin Reiss, David Serlin, and Rachel Adams (New York: New York University Press, 2015), 14.

⁴ Williamson, “Access”, 14.

⁵ Hans Christian Andersen, “Thumbelina”, in *Hans Christian Andersen’s Complete Fairy Tales*, trans. Jean Hersholt (San Diego: Printers Row Publishing, 2014), 19. All further references to the fairy tale will be given in the body of this paper.

⁶ Rachel Adams, “Disability”, in *Keywords for Disability Studies*, eds. Benjamin Reiss, David Serlin, and Rachel Adams (New York: New York University Press, 2015), 9.

feature of a disabled identity is not the *nature* or *extent* of the impairment, but the political experience of oppression' that results from it.⁷ Individuals who experience disability 'undergo a wide range of experiences as the direct result of their impairment, and some identity-forming experiences may be better be described as exclusion, rejection or isolation'.⁸ Here, Watson's preoccupation with the social experiences that construct disability can be used to interpret Thumbelina. Her smallness is not an impairment within itself; rather, her interactions with other characters are disabling because she experiences 'exclusion' and 'rejection' as a result of her physical difference.

Engaging with visual forms alongside the fairy tale, I explore 'the potential for literature to act as a site of resistance or creative reimagining' of disability through illustration and Andersen's own paper art.⁹ In doing so, I show how artistic depictions of 'Thumbelina' have the potential to reflect or underscore Andersen's literary representation of issues relating to gender and disability. As Chloë Hughes argues: 'the visual conduits of meaning in picturebooks may speak volumes about societal issues like disability, and may even undermine written messages'.¹⁰ Alongside my analysis of illustration, I examine three examples of Andersen's paper art, an area of critical enquiry that has gone largely unacknowledged by scholars. In one of the only studies on the subject, Beth Wagner Brust – who investigates Andersen's paper art but does not consider the 'Thumbelina' fairy tale – claims that the 'paper cuttings enchanted everyone who saw them', as Andersen 'usually made his cuttings while people watched, often while he was telling a fairy tale aloud'.¹¹ Considering the role of art within a broader context of fairy tales, gender, and disability, I am attentive to the artistic and political possibilities of disability, an idea supported by Tobin Siebers who claims that '[d]isability is now and will be in the future an aesthetic value in itself'.¹²

Critical engagements with disability and 'Thumbelina' are piecemeal; however, Vivian Yenika-Agbaw does read 'Thumbelina' through a disability framework. Using legal disability criteria, Yenika-Agbaw interprets the character of Thumbelina through the condition of dwarfism. I do not adopt this diagnostic approach, but I do agree that social environments,

⁷ Nick Watson, *Routledge Handbook of Disability Studies* (Oxon: Routledge, 2020), 146 (emphasis in original).

⁸ Watson, *Routledge Handbook of Disability Studies*, 146.

⁹ Alice Hall, *Literature and Disability* (Oxon: Routledge: 2016), 34.

¹⁰ Chloë Hughes, "Seeing Blindness in Children's Picture Books", *Journal of Literary and Cultural Disability Studies* 6, no. 1 (2012): 36.

¹¹ Beth Wagner Brust, *The Amazing Paper Cutting of Hans Christian Andersen* (Boston: Houghton Mifflin Company, 1994), 11; 12.

¹² Tobin Siebers, *Disability Aesthetics* (Michigan: University of Michigan, 2010), 139.

where Yenika-Agbaw claims that it is important to interrogate ‘how characters interact and share space as males/females, adults/children, and as people with or without disabilities’, enable the text to be read in this way.¹³ As Yenika-Agbaw further states, Thumbelina ‘remains an object of curiosity, pity, and admiration because of her size’.¹⁴ Other recent scholars have investigated the theme of gender in the tale, but work that combines literary analysis with visual forms is yet to be undertaken.¹⁵ By offering one of the first explorations into literary representations of disability, gender, and visual forms together, this paper bridges gaps in Children’s Literature and Literary Disability Studies. In particular, I argue that interdisciplinary approaches account more fully for the social, gendered, literary, and artistic contexts associated with disability, thereby building on Brewer *et al*’s argument that ‘[i]f disability is seen, written about, and represented artistically, it becomes one location on a continuum that includes all humans.’¹⁶

In ‘Thumbelina’, themes including accessibility, physical ability, and the environment overlap with disability concerns. However, through ‘Thumbelina’, Andersen also celebrates female agency and a positive sense of disabled community. My aims for analysing the fairy tale are three-fold: first, to examine how the may-bug characters are used to call attention to Thumbelina’s gendered and bodily constraints; second, to explore how the swallow allegorically represents Thumbelina’s emancipation from an inhospitable physical environment; and third, to interrogate how Andersen’s presentation of the flower-prince and his kingdom is nuanced. The flower-prince’s position in the text does promote equitable relationships between characters with physical differences, but Thumbelina’s arrival in the flower kingdom further undermines her sense of identity and reinscribes a normative sense of able-bodiedness.

¹³ Vivian Yenika-Agbaw, “Reading Disability in Children’s Literature: Hans Christian Andersen’s Tales”, *Journal of Literary and Cultural Disability Studies* 5, no. 1 (2011): 104.

¹⁴ Yenika-Agbaw, “Reading Disability in Children’s Literature”, 98.

¹⁵ See for example Maria Holmgren Troy, “Imagining Gender in Nineteenth-Century Fairy Tales by Hans Christian Andersen and Richard Henry Stoddard”, *Nordic Journal of English Studies* 19, no. 4 (2020) and Michalina Grzelka, “Representation of Disability in Fairy Tales from the Perspective of the Social Model of Disability”, *International Journal of Pedagogy, Innovation, and New Technologies* 6, no. 1 (2019).

¹⁶ Elizabeth Brewer, Brenda Jo Brueggemann, Nicholas Hetrick, and Melanie Yergeau, “Introduction, Background, and History”, in *Arts and Humanities: Disability Key Issues and Future Directions*, ed. Brenda Jo Brueggemann (California: Sage Publications, 2012), 10.

The overlap between Thumbelina's physical smallness and her feminine beauty also compounds her subordination in the text. Disability scholar Rosemarie Garland-Thomson highlights the link between female bodies and disabled bodies:

Both the female and the disabled body are cast as deviant and inferior; both are excluded from full participation in public as well as economic life; both are defined in opposition to a norm that is assumed to possess natural physical superiority.¹⁷

Garland-Thomson's argument can be used to interpret Thumbelina; she is 'a good and pretty girl' (23) who is subject to the affections of male creatures including a toad, a may-bug, and a mole. However, she is treated as 'inferior' because she is physically controlled and experiences stigma as a result of both her feminine passivity and her smallness. Furthermore, Thumbelina's floral characterisation heightens her femininity. Beverley Seaton pinpoints the links between flowers and femininity in a gendered context, claiming that 'flowers were seen as the most suitable aspect of nature to represent women' through 'certain stereotypical qualities of the female being: smallness of stature, fragility of mind and body, and impermanence of beauty'.¹⁸ This idea can be seen through Thumbelina's physical description. Thumbelina is born out of a flower, and the underdeveloped flower mirrors her small height, as Andersen writes: 'It quickly grew into a fine large flower [...] but the petals were folded tight, as though it were still a bud', and she is 'as frail and fine as the petal of a rose' (19).

After escaping an arranged marriage with a toad at the beginning of the tale, Thumbelina encounters a may-bug in her travels through the natural world. The may-bug 'fastened his claws around her slender waist and flew up with her into a tree', and he 'sat her down on the largest green leaf of the tree, fed her honey from the flowers, and told her how pretty she was' (20). Whilst Andersen at first demonstrates how Thumbelina resists her feminine role by rejecting the toad and his proposal of marriage, as 'she didn't want to have the toad's horrible son for the husband' (20), the may-bug forces her back into a subordinated position. The may-bug commandeers Thumbelina's small body and removes her mobility, and in doing so he also reinforces feminine traits of passivity and aesthetic value. As a result, Thumbelina becomes a decorative object rather than an independent character, and the may-bug is used to curtail female agency and reinscribe gender conformity.

¹⁷ Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Literature and Culture* (New York, Columbia University Press, 1997), 19.

¹⁸ Beverley Seaton, *The Language of Flowers: A History* (London: The University Press of Virginia, 1995), 17.

The male may-bug calls attention to themes of accessibility, immobility, and idealised femininity, whilst the female may-bugs communicate stigma and hostility, which can also be understood in line with disability. Andersen writes the following:

“Why, she has only two legs - what a miserable sight!”

“She hasn't any feelers,” one cried.

[...]

“She looks like a human being - how ugly she is!” said all of the female Maybugs.

Yet Thumbelina was as pretty as ever. Even the Maybug who had flown away with her knew that, but as every last one of them kept calling her ugly, he at length came to agree with them and would have nothing to do with her. (20-1)

Here, Thumbelina's aesthetic differences are admired by the male may-bug but criticised by female characters. Thumbelina is rejected as a result of her physical difference, which is made visible in a social context here, and this can be analysed using disability frameworks. The concept of the 'aesthetic' has a critical utility in Disability Studies, and Michael Davidson asserts that 'aesthetic judgments implicate disability insofar as they presume a normative standard of perception and an ideal of bodily perception'.¹⁹ Furthermore, Siebers states that 'all bodies are not created equal when it comes to aesthetic response. Taste and disgust are volatile reactions that reveal the ease or disease with which one body might incorporate another'.²⁰ In becoming antithetical to the female may-bugs' normative bodily standards, then, Thumbelina is socially excluded and perceived as non-normative. This occurs on the basis of her physical appearance rather than any discernible impairment, but her social exclusion emphasises her marginalisation. As Yenika-Agbaw claims, '[in] the human and natural worlds, the larger people/animals/objects serve as colonial masters, as they also objectify and reduce [Thumbelina] to a freak of nature'.²¹ The male may-bug values Thumbelina's beauty whilst the female may-bugs are more critical about her physical difference from them, therefore ostracising and positioning her as the 'other'. This ultimately demonstrates how – in line with the social model of disability – disability is inherently a social and political issue.

¹⁹ Michael Davidson, "Aesthetics", in *Keywords for Disability Studies*, eds. Benjamin Reiss, David Serlin, and Rachel Adams (New York: New York University Press, 2015), 26.

²⁰ Siebers, *Disability Aesthetics*, 1.

²¹ Yenika-Agbaw, "Reading Disability in Children's Literature", 97.

After she is rejected by the may-bugs, Thumbelina is rescued by a mouse; yet, despite her ‘kind-hearted’ (21) disposition, the mouse further imposes social norms of femininity. For example, the mouse instructs Thumbelina to marry her neighbour the mole, a ‘sensible man’ (22), and when Thumbelina refuses the mouse threatens her with violence: ‘Don’t you be obstinate, or I’ll bite you with my white teeth. Why, you’re getting a superb husband [...] You ought to thank goodness that you are getting him’ (24). Maria Holmgren Troy recently examined the ‘Thumbelina’ tale, and she states that ‘older female characters actively work to uphold social norms and patriarchy by finding and grooming a beautiful and submissive wife’.²² The mouse sustains and promotes patriarchal values that subordinate women through marriage and, in juxtaposing the mouse’s views with Thumbelina’s feminist defiance, Andersen anticipates the cultural conflict between the Angel in the House and the New Woman figures that would unfold as the nineteenth century progressed. Although Andersen was writing many of his fairy tales several years before these constructs emerged, he places Thumbelina and the mouse in conflict in order to demonstrate contrasting viewpoints of normative feminine behaviour. For some time following this incident, Thumbelina is trapped by the mouse and mole, seemingly unable to escape her predicament. Eventually, however, Thumbelina is saved by a more amicable creature – a swallow – who aid hers escape: ‘tie yourself on with your sash, and away we’ll fly, far from the ugly mole and his dark hole-far, far away’ (24).

Figure One: Hans Tegner,
“Thumbelina Seated Herself on the Swallow’s Back”



Figure Two: Charles Robinson, “Then She Sat Down on the Bird’s Back”

²² Holmgren Troy, “Imagining Gender in Nineteenth-Century Fairy Tales”, 68.

It is productive to consider illustration here in order to understand the swallow's overarching purpose in the tale. The swallow works to remove Thumbelina from the mouse and mole's oppression, social stigma and hostility, and the inaccessible barriers of the natural world. The first illustration was produced by the Danish illustrator Hans Tegner in 1911. It depicts the mouse and the mole in a dark underground hole. This metaphorically represents the oppression associated with both the natural world and Thumbelina's prospective marriage, and the swallow's ability to aid Thumbelina allegorically functions as a type of prosthesis. According to Katherine Ott, prosthesis refers to 'assistive devices that people use to support what they want to do'.²³ She further explains that, in a context of disability, 'a prosthesis can function as a social symbol and a political allegory for one's self', which can be seen here as the swallow assists Thumbelina in overcoming her plight.²⁴ Figure Two was created by the British illustrator Charles Robinson, and it was published in *The Big Book of Fairy Tales* in 1911. The black and white image represents the moment where Thumbelina is removed from an equally uninviting, colourless world. She is surrounded by clouds, and according to Jacqueline Taylor Basker clouds in literature have ambivalent meanings, symbolising 'the generative, the destructive, and the enigmatic'.²⁵ This idea parallels with Thumbelina's position here: she anticipates positive change in the flower kingdom, but Andersen's nuanced representation of this moment complicates her agency further. Further, the large, hostile mountains further emphasise Thumbelina's physical smallness and function as a suitable metaphor for her struggles until this point. As Grzelka claims: "'Thumbelina" is a good example of how hostile an inaccessible environment can be to people with disabilities', yet these illustrations do also point to hope and positivity since the swallow helps Thumbelina to overcome her obstacles.²⁶

Following her escape from the mouse and mole, Thumbelina's physical difference is accepted when she meets characters of her own kind at the end. Like Thumbelina, the flower-prince develops out of a flower: 'In every flower there lived a small man or woman just like him' (25). Andersen's description of this moment is complex and can be nuanced. On the one hand, the flower-prince polices the flower community, and the tale's marriage denouement undermines female agency. Thumbelina submits to a male character, and her smallness is 'cured' through marriage. For example, the flower-prince gifts Thumbelina wings in order to

²³ Katherine Ott, "Prosthetics", in *Keywords for Disability Studies*, eds. Benjamin Reiss, David Serlin, and Rachel Adams (New York: New York University Press, 2015), 140.

²⁴ Ott, "Prosthetics", 140.

²⁵ Jacqueline Taylor Basker, "The Cloud as Symbol: Destruction or Dialogue", *Cross Currents* 11 (2006): 111.

²⁶ Grzelka, "Representation of Disability in Fairy Tales from the Perspective of the Social Model of Disability", 111.

overcome mobility issues presented by her small height, and he changes her name because her existing one is ‘ugly’: ‘[y]ou shall no longer be called Thumbelina [...] We shall call you Maia’ (25). Thumbelina’s name, a name that first encapsulated her smallness (‘she was no taller than your thumb. So she was called Thumbelina’, 19), suggests that her impairment must be ‘cured’ in line with the medical model of disability. On the other hand, however, Andersen does restore social order by uniting Thumbelina with a character of her own kind, thereby presenting a more positive view of disabled community in contrast to the stigma, ableism, and alienation that she experienced previously. Therefore, although Andersen does not destabilise and rectify gendered and ableist norms, he does portray more equitable relationships between characters who are otherwise excluded through their physical difference, ultimately creating ‘a more inclusive society with greater opportunities for social and political participation’.²⁷

Themes of gender and disability in the tale can be explored further through Andersen’s own paper art. During his writing of the fairy tales, Andersen produced many paper cuttings, and nearly four hundred survive today. In one 1867 letter, Andersen states that ‘paper cutting is the prelude to writing’, and according to art historian Detlef Klein these cuttings were ‘made with a great deal of purpose’.²⁸ Andersen’s paper cuttings are not directly based on his fairy tales, but it is still possible to interpret them through themes of gender and disability as seen in ‘Thumbelina’. As noted in the sleeve notes to the collection of Andersen’s paper cuttings, often ‘there was a hidden meaning in the paper cuttings – in the same way, as we know it from the fairy tales: on the surface it could amuse, in the depth it would amaze’.²⁹ Moy McCrory states the following in her article on the subject:

In his paper cut outs [Andersen] worked with something tangible, an external reality which reflected his own imagination and a possible place of belonging, which he might bring into being for a brief flare of life. At these times, he was able to hold in his hands a potential of what could exist and imagine being in a less defined world.³⁰

McCrory’s claim that Andersen’s paper cuttings reflect ‘a possible place of belonging’ links back to Thumbelina and her social exclusion within an inhospitable social environment. McCrory also highlights how art – as well as literature – can be used to mobilise and explore

²⁷ Williamson, “Access”, 14.

²⁸ “Hans Christian Andersen’s Lesser-known Talent: Paper Cuttings”, *DW*, Oct 19, 2018, Accessed Feb 19, 2022, <https://www.dw.com/en/hans-christian-andersens-lesser-known-talent-paper-cuttings/a-45924839>

²⁹ Moy McCrory, “Andersen’s Scissors: Cutting His Own Shape”, *Writing in Practice* 5 (2019), para. 67.

³⁰ McCrory, “Andersen’s Scissors: Cutting His Own Shape”, para. 84.

more creative possibilities as a way of imagining a better future and ‘a less defined world’. The materiality of the paper cuttings also merit attention here; as physically fragile artefacts, the paper cuttings function as a suitable metaphor for the character of Thumbelina herself, who is repeatedly described as ‘dainty’ (19) and is ‘so slender and frail’ (21). Just as Thumbelina’s body is easily controlled by other characters in the story, Andersen’s paper cuttings are so fragile that ‘[y]ou could often bend the figures a little, blow at them and then move them across the tabletop’.³¹

Figure Three: Hans Christian Andersen, “The Botanist”



Figure Three shows a paper cutting by Andersen that is described by Klein as ‘a living flower that has feelings’.³² Through his paper cutting, Andersen anthropomorphises a plant in human-like form. McCrory suggests that ‘Andersen’s possible life was cut and re-cut [...] a dream turned into a paper cut out, a series of figures through which he allowed light to shine, projecting the possibility and the possible life’, which reflects the uncanniness of this image as well as Thumbelina’s own ability to overcome obstacles within nature. The flower figure is depicted as bold and threatening rather than passive and delicate. This underscores the traditional correlation between femininity and flowers in the nineteenth century that I discussed previously, and the fact that the flower figure is intimidating (with its arched eyebrows, menacing smile, and thorny features) may allegorically represent the hostility of the natural world in ‘Thumbelina’. Furthermore, McCrory’s assertion that Andersen ‘made things fit into his world, rather than his being made to fit inside the conventions of his time’ encapsulates how Andersen moves away from the Victorian feminine ideal here, creating a paper cutting that embodies the hostility, rather than the passivity, of the natural world.³³

³¹ “The Exquisite, Ephemeral Paper Cuttings of Hans Christian Andersen”, *Open Culture*, March 1, 2021, Accessed Feb 19, 2022, <https://www.openculture.com/2021/03/the-exquisite-ephemeral-paper-cuttings-of-hans-christian-andersen.html>

³² “Hans Christian Andersen’s Lesser-known Talent: Paper Cuttings.”

³³ McCrory, “Andersen’s Scissors: Cutting His Own Shape”, para. 4.

Figure Four: Hans Christian Andersen, “Ballerinas in a Corked Bottle”

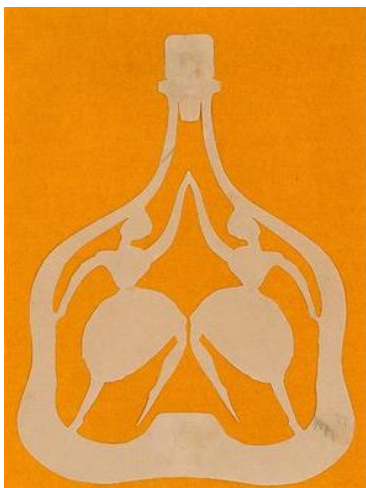


Figure Five: Hans Christian Andersen, “Hands from Above”



By comparison, Figures Four and Five convey feminine figures that are entrapped or without agency. In Figure Four, Andersen depicts two ballerina figures enclosed in a corked glass bottle, and this sense of enclosure and the inability to escape reinforces themes in ‘Thumbelina’. However, this view becomes more complicated still since the two figures are joined together in an act of unity. This unity may metaphorically signify Andersen’s own sympathies or solidarity with female struggles given his own status as a social outcast. As J. N. Frandsen suggests, Andersen ‘takes a position on societal values and he always sides with the weak and fragile, the children, the outcast, and the strange and odd characters’, whilst Wagner Brust further states that ‘[i]n his cuttings [Andersen] reveals both the fantastic world of his imagination and glimpses of his life’.³⁴ Moreover, Figure Five, which is entitled ‘Hands from Above,’ depicts another helpless feminine figure. This figure, like Thumbelina, is physically small and captured by a larger creature. The cutting reinforces the moment in ‘Thumbelina’ where the titular character is captured by the male may-bug, who ‘fastened his claws around her slender waist and flew with her up into a tree’ (20). The red background of the cutting also has connotations of danger; as Michel Pastoureau explains: ‘[r]ed [...] is always connected to the idea of something dangerous.’³⁵ This further emphasises the unequal power dynamics

³⁴ J. N. Frandsen, “Hans Christian Andersen: Human Values and Ethical Literature: An Introduction”, *Forum for World Literature Studies* 11, no. 2 (2019): 1; Wagner Brust, *The Amazing Paper Cutting of Hans Christian Andersen*, 14.

³⁵ Michel Pastoureau, *Red: The History of a Color*, trans. Jody Gladding (Princeton: Princeton University Press, 2017), 178.

between identity groups – male and female characters, able-bodied and disabled – that are seen in both the tale and Andersen’s art.

In this paper, I have offered some exploratory insights into Hans Christian Andersen’s ‘Thumbelina.’ I have analysed some representations of femininity and disability in the fairy tale whilst also drawing on associated visual forms, namely illustrations and paper art, to extend the critical utility of these interpretations. I have demonstrated how ‘Thumbelina’ and its associated visual forms reveal complex, nuanced attitudes towards femininity and disability. On one level, Andersen upholds feminine and ableist norms. However, on another level he does reveal a degree of sympathy and promotes individual agency, presenting a female character who overcomes an inhospitable, inaccessible physical environment in order to foster more equitable relationships with other characters who share her physical difference. Fairy tale scholar Jan Ziolkowski ultimately suggests that ‘it seems fruitless to press these stories for one overarching meaning or seek any one interpretation’.³⁶ It is this complexity that enables Andersen’s work – and the visual forms that are directly or indirectly influenced by his work – to be read in a multitude of different ways.

³⁶ Jan Ziolkowski, *Fairy Tales from Before Fairy Tales* (Michigan: University of Michigan, 2009), 105.

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Gender Bias in Medical Implant Design and Use: A Case of Epistemic Injustice

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Introduction

Gender disparity in medical implant design and use causes pain and discomfort for the women who use them. There are reports of women suffer more because of using medical implants. According to these reports, women's sexual needs are not considered, in for example, hip replacement. In this oaoer, I explore this issue, focusing mainly on artificial joints such as hips and knees. In the first part, I outline the problem of disproportionate and unacceptable levels of implant failure in women's sexual lives. Then, in the second part, I will analyze the issue from epistemic injustice perspective by focusing on testimonial and hermeneutical injustice.

Women's sexual needs, especially during intercourse have not been adequately reflected in artificial hip designs: "Unfortunately, the sexual activities of patients are not addressed in most of the traditional hip scoring systems or self-assessment questionnaires currently in use."² Although, Total Hip Arthroplasty (THA) has impacted the sexual activities of both men and women, women have been more disadvantaged. For example, a study reported: "We found that hip arthritis limited the sexual life of 82% (131 of 159) of those patients who ultimately underwent primary THA. Ninety-six percent (68 of 71) of women reported sexual limitations, whereas only 72% (63 of 88) of men did."³

There are also other studies with similar conclusions; in conclusion we found that many patients undergoing THA are sexually active, but most patients have limitations in their sexual activities as a result of their hip arthritis. Women are more affected than men. There is increased pain and reduced flexion and external rotation among those patients who report sexual limitations. Sexual difficulties resulting from hip arthritis affect the quality of life of patients. Before surgery, counseling on sexual activities should be routinely discussed with all patients undergoing THA.⁴

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² Lieberman JR, Thomas BJ, Finerman GA, Dorey F. "Patients' reasons for undergoing total hip arthroplasty can change over time." *J Arthroplasty*. 2003;18:63-68 10.1054/arth.2003.50010.

³, C. J. Lavernia and J. M. Villa, "High rates of interest in sex in patients with hip arthritis," *Clinical Orthopaedics and Related Research* 474, no. 2 (201): 6294.

⁴ Lavernia and Villa, "High rates," 298.

The last point of this report is indicating an important issue, which needs to be discussed in the literature. Discussing the impacts of THA on the patients' sexual activities could be of great help. However, it seems like health care providers -for the most part- the surgeons do not discuss these issues with their patients, especially women. In a survey of members of the American Association of Hip and Knee Surgeons performed by Dahm et al.⁵, 80% of surgeons reported that they rarely or never discuss sexual activity with their patients undergoing hip arthroplasty. Ninety-six percent of those surgeons who discussed the subject spent 5 minutes or less in such discussion. Lavernia and Villa also had similar findings that orthopedic surgeons rarely discuss sexual activity with patients undergoing THA.⁶

There is a recent detailed motion-capture study, which shows that there are significant differences in the range of motion and stress on the hip joint during sexual intercourse for women and men.⁷ According to this study, among twelve different sexual positions eleven of them were safe for men. However, only eight were safe for women. Only the positions did not require movement beyond the limits of the artificial joint were safe for women. Otherwise, non-safe sex positions for women could lead to dislocation, higher wear due to the impact of pressure on the edge of the artificial hip, and breaking the edge of the socket, which could occur during sexual intercourse. In summary, study demonstrated some sexual positions could be hence potentially at risk after THA, particularly for women. This study can provide precious data for the clinicians to use and discuss with their patients to provide safer sexual activities after THA.

⁵ Dahm DL, Jacofsky D, Lewallen DG. Surgeons rarely discuss sexual activity with patients after THA: a survey of members of the American Association of Hip and Knee Surgeons. *Clin Orthop Relat Res.* 2004;428:237-240

⁶ Lavernia and Villa, 293-99.

⁷ Charbonnier, Caecilia, Chagué, Sylvain, Ponzoni, Matteo, Bernardoni, Massimiliano, Hoffmeyer, Pierre, and Christofilopoulos, Panayiotis, "Sexual activity after total hip arthroplasty: A motion capture study," *Journal of Arthroplasty* 29, no. 3 (2014): 640-47.

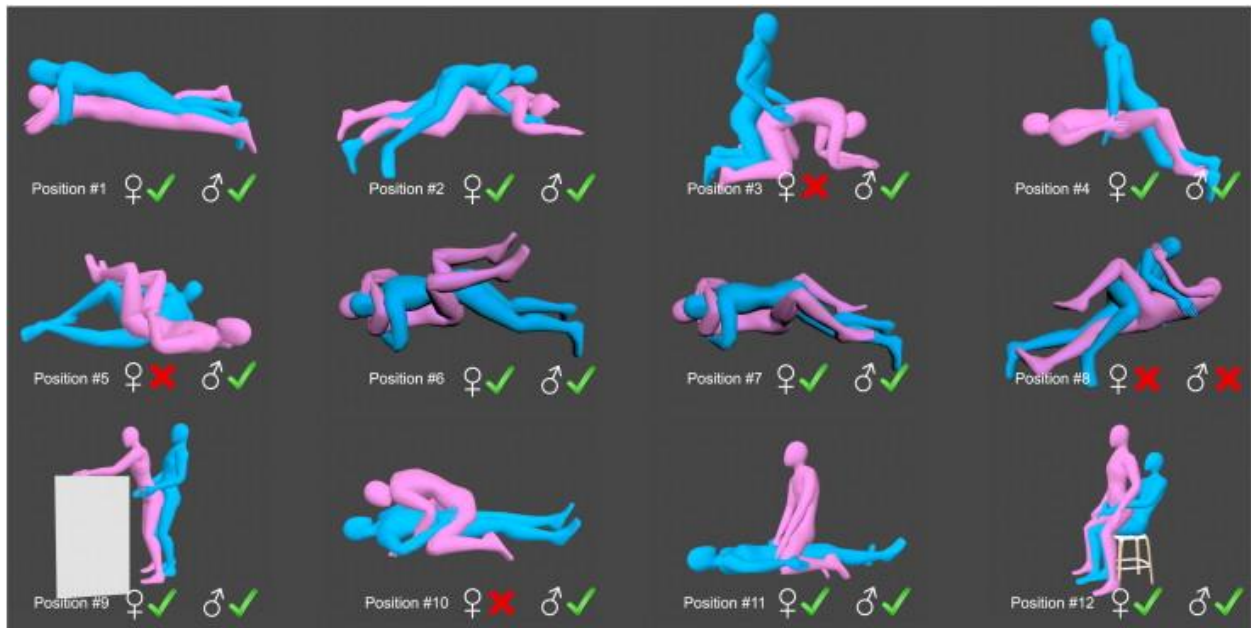


Figure 1 The twelve common sex positions demonstrated by a man (blue) and a woman (pink).⁸

The problem of lack of clinical consultations about the impacts of medical devices on women's personal lives is a complicated and systematic issue. Evidence shows that clinical consultations are influenced by clinician and patient gender in ways that disadvantage women. For example, a study showed that among all the different models, the combination of male clinician and female patient appears to be less patient-centered than other gender combinations, and clinicians are more paternalistic in this combination.⁹

Another contributing issue is the disproportionate number of men orthopedic surgeons and women patients. Orthopedic surgery has the lowest representation of women of all surgical specialties—6.5% in the US. On the other hand, “Data indicate that 62% of all THR procedures that are performed in the United States are on women, with 2/3 of these procedures performed in individuals older than 65 years of age.”¹⁰ As a result, the combination of male clinician and female patient is common in hip replacement.¹¹ By considering these statistics in mind, it would

⁸ Charbonnier et. al. “Sexual activity,” 646.

⁹ Sandhu, Harbinder, Adams, Ann, Singleton, Laura, Clark-Carter, David, and Kidd, Jane. “The impact of gender dyads on doctor–patient communication: A systematic review,” *Patient Education and Counselling* 76, no. 3 (2009): 348–55.

¹⁰ Meiri, Rotem, Rosenbaum, Talli Y., and Kalichman, Leonid. “Sexual function before and after total hip replacement: Narrative review,” *Sexual Medicine* 2, no. 4 (2014): 161.

⁹ American Academy of Orthopedic Surgeons. 2019. Making the Case (Again) for Gender Equity. June 1.

¹¹ <https://www.aaos.org/aaosnow/2019/jun/youraaos/youraaos05/>

be explained why there is poor communication between clinicians and their female patients about sex after hip replacement.

Laffosse, et al. discuss this issue as:

Our study confirms our hypothesis concerning the negative consequences of chronic hip pain on the sexual activity of our patients. The patients most affected are young women who are also affected the earliest, and those with hip dysplasia are at-risk patients. Undergoing THA will offer an improvement of the difficulties. This problem needs to be broached with patients and they need to be given clear and detailed information, in particular concerning a period of abstinence to be observed for at least 1 month, and the at-risk positions. Lack of knowledge of these problems is, for the most part, due to lack of information given by surgeons and/or nursing staff, but also because patients do not feel comfortable talking about them openly. A clear and simple booklet would help promote dialogue between health care personnel and patient, but also between the patient and their partner.¹²

As is mentioned in above quotation, poor communication between surgeons and their women patients causes lack of knowledge to address women's sexual needs after THA. This lack of knowledge is a case of injustice that I will discuss in the next part.

Epistemic Injustice

Feminist epistemologists and Standpoint theorists argue that philosophical inquiry must take the social contexts from which both philosophical questions emerge and responses to them are generated more seriously. Some of these social contexts could include the subjectivity and social positioning of any given questioner and respondent. They argue information about the subjectivity and social situation of knowers can provide valuable insights into the assumptions and biases on which a given position relies.¹³ For example, Alison Wylie says:

[T]hose who are subject to structures of domination that systematically marginalize and oppress them may, in fact, be epistemically privileged in some crucial respects. They may know different things, or know things better than those who are comparatively privileged (socially, politically) by virtue of what they experience and how they understand their experience. Feminist standpoint theorists argue that gender is one dimension of social differentiation that may make a difference epistemically. Their aim is to both understand how the systematic partiality of authoritative

¹² Laffosse, Jean-Michel, Tricoire, Jean-Louis, Chiron, Philippe, and Puget, Jean. "Sexual function before and after primary total hip arthroplasty," *Joint Bone Spine* 75, no. 2 (2008): 193.

¹³ For example, see: Harding, Sandra. *Whose science? Whose knowledge?*. Cornell University Press, 2016.

knowledge arises—specifically, its androcentrism and sexism—and to account for the constructive contributions made by those working from marginal standpoints (especially feminist standpoints) in countering this partiality.¹⁴

Women patients' standpoint and knowledge is vital for implant design and use. However, because of a variety of epistemic injustices, it is not happening. There are different kinds of epistemic injustice occurring in the case of implant design and use. One of them is epistemic exclusion, which indicates there are certain kinds of knowledge refused admission into general shared stock. This happens when there are oppressive power relations in action, and certain social groups are marginalized. In the case of medical implants, women who get hip replacement are the people who are epistemically excluded to share their experience of sexual activities after their hip replacement surgeries. Especially, since most of the orthopedic surgeons are men, there is also oppressive power relation in action. In this epistemic power relation, the male surgeons have epistemic authority over women patients. Epistemic authority is defined as: Some people can legitimately establish and enforce epistemic practices such as decide the criteria for credibility, organize the routes through which knowledge is fed into public discourse or policy debates, and so on.

Another kind of epistemic injustice is hermeneutical injustice. Hermeneutical injustice occurs when someone's experiences are not well understood — by themselves or by others — because these experiences do not fit any concepts known to them (or known to others), due to the historic exclusion of some groups of people from activities, such as scholarship and journalism.

Miranda Fricker (2007) argues that the capacity of relatively powerless social groups to adequately and appropriately understand the world is jeopardized if dominant groups disproportionately influence the interpretive resources available at any given time asymmetrical relations of social power, she explains, can skew shared hermeneutical resources in ways that both enable members of powerful social groups to understand their social experiences and prevent members of relatively disempowered social groups from understanding their own experiences.¹⁵ She puts it:

¹⁴ Wylie, Alison, Robert Figueroa, and Sandra Harding. "Why standpoint matters," *Science and other cultures: Issues in philosophies of science and technology* 26 (2003): 26.

¹⁵ Miranda Fricker, *Epistemic injustice: Power and the ethics of knowing* (Oxford University Press, 2007), 146-8.

If, for instance, someone has a medical condition affecting their social behavior at a historical moment at which that condition is still misunderstood and largely undiagnosed, then they may suffer from a hermeneutical disadvantage that is, while collective, especially damaging to them in particular. They are unable to render their experiences intelligible by reference to the idea that they have a disorder, and so they are personally in the dark, and may also suffer seriously negative consequences from others' non-comprehension of their condition. (p.152)

In the case of women with hip replacement, their collective experiences during sex have been ignored and not well understood. One of the main harms of this injustice is women's painful experiences during intercourse. In this situation, the disabled person is well able to understand her experience and to articulate it to others. But the disabled person's claims "fail to gain appropriate uptake according to the biased hermeneutical resources utilized by the perceiver."¹⁶ Pohlhaus (2012)¹⁷ calls this *wilful hermeneutical ignorance*—wilful, because the listeners do have the option of recognizing, or suspecting, their epistemic limitations and acting accordingly. The dominant group *contributes* to the injustice by refusing to engage with marginalized groups' epistemic resources (e.g. women's sexual experiences after hip replacement) and insisting on comprehending them solely within their own terms.

Katrina Hutchison (2019) argues part of the problem is because of gender bias:

Advice about specific types of risk, such as those associated with sexual activity, may be particularly susceptible to gender bias. As a consequence of the design limitations of hip prostheses, women are more likely than men to have more limited sex lives following a hip replacement. This disparity is typical of the wider trend to downplay women's sexual problems, including the impact of disease and treatment on women's sex lives.¹⁸

In the case of women after hip replacement, although there is gender bias issue, I mostly see the problem as biases against the intersection of gender and disability, as the important part of these women's identity. Testimonial injustice occurs when the knower, because of her identity, does not have credibility to be believed. A woman with a disability because of her identity is denied to have sexual needs and desire after hip replacement. There is a long-held stereotype

¹⁶ Dotson, Kristie. "A cautionary tale: On limiting epistemic oppression," *Frontiers: A Journal of Women Studies* 33, no. 1 (2012): 32.

¹⁷ Pohlhaus, Gaile. "Relational knowing and epistemic injustice: Toward a theory of willful hermeneutical ignorance," *Hypatia* 27, no. 4 (2012): 715-735.

¹⁸ Katrina Hutchison, "Gender bias in medical implant design and use: a type of moral aggregation problem?" *Hypatia* 34, no. 3 (2019): 576.

that these women are asexual.¹⁹ There are different explanations for the association of non-sexuality and disability in women. Heyman and Huckle (1995) link the sexuality taboo to the fear that women with disabilities will give birth to “defective” children, which makes them “unfit” for motherhood.²⁰ This explanation was considered scientifically a legitimate one to justify the sterilization of tens of thousands of women in the twentieth century for the eugenicists. Decades after banning the eugenics movement in the US, however, denying and controlling disabled women’s sexuality is still occurring.

If the people who are involved in hip design and replacement surgery have this assumption about women with disabilities, it would be one of the main causes of women’s suffering during sex after hip replacement therapy. In the case of hip replacement therapy, not only 80% of surgeons do not initiate conversations about women’s sex life after the surgery for reasons such as “feeling uncomfortable about raising the topic,” but also “surgeons are more likely to initiate conversations about sex with younger patients and with married patients.”²¹ The Surgeons’ willingness to discuss sex after surgery with married and young women could indicate the mentioned bias about disabled women’s sexuality. This fact is an example of applying non-epistemic value judgements to medical knowledge and treatment. The exclusion of unmarried and older women patients from the conversations about sex after the surgery is also an example of epistemic exclusion. This case of epistemic exclusion is caused by both institutional and individual level factors. The institutional level factor is the disproportionate distribution male and female surgeons and women patients. The individual level factor is the personal biases of surgeons about the sexuality of different groups of women with disabilities. A combination of these factors causes the denial and ignorance of the sexual needs of women with disabilities.

¹⁹ For more explanation and examples. See: Ferri and Gregg, “Women with disabilities.”

²⁰ Ferri and Gregg, 431-432.

²¹ Diane L. Dahm, David Jacofsky and David G. Lewallen, “Surgeons rarely discuss sexual activity with patients after THA: A survey of members of the American Association of Hip and Knee Surgeons,” *Clinical Orthopaedics and Related Research* (2004): 428: 238.

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Bringing Visibility to Invisibility: Examining the Complexities of “Invisibility” amongst Students with Disabilities in Higher Education

Stacie L. Warner¹

Introduction

In recent years, higher education institutions have emphasized adopting equitable and inclusive learning practices that cater to the enrollment, retention, and support of diverse bodies of learners, including learners with disabilities. Higher education is generally deemed integral to career acquisition, development, and success and viewed as a gateway to opportunity and superb quality of life. Accessibility to higher education is considered more significant for individuals with physical and sensory disabilities, especially if the individuals have a limited range of employment possibilities based on abilities or skills.² Subsequently, the number of students with disabilities enrolled in higher education has continued to increase over the years.³ Students with disabilities constitute 11% of enrolled learners in higher education institutions in the United States (US) and “continue to be confronted with difficulties in higher education as “the most recent marginalized group to gain full access to the American dream” due to academic, legal, financial and institutional obstacles.”⁴ Unfortunately, higher education reinforces numerous societal and cultural ills regarding disability, including fostering invisibility.

Invisibility

Invisibility can refer to a range of actions or practices that reinforce marginalization, discrimination, or oppression by exclusion. Invisibility results from individuals or groups being ignored, overlooked or unrecognized, unsupported, segregated, or miss or underrepresented. It

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² Dalia Sachs and Naomi Schreuer, “Inclusion of Students with Disabilities in Higher Education: Performance and participation in student's experiences,” *Disability Studies Quarterly* 31 (2011): n. pag.

³ Lynn Clouder et al, “Neurodiversity in higher education: A narrative synthesis,” *Higher Education* 80, no. 4 (2020); Emily Ehlinger and Rebecca Ropers, “It's All About Learning as a Community: Facilitating the Learning of Students with Disabilities in Higher Education Classrooms,” *Journal of College Student Development* 61, no. 3 (2020); Edlyn Vallejo Peña, “Marginalization of published scholarship on students with disabilities in higher education journals,” *Journal of College Student Development* 55, no. 1 (2014); Sharlene A Kiuahara and Dixie S. Huefner, “Students with psychiatric disabilities in higher education settings: The Americans with Disabilities Act and beyond,” *Journal of Disability Policy Studies* 19, no. 2 (2008).

⁴ Nina Yssel, Natalya Pak, and Jayne Beilke, “A door must be opened: Perceptions of students with disabilities in higher education,” *International Journal of Disability, Development and Education* 63, no. 3 (2016), 384.

is generally predicated on a construct like race, gender, class, disability, or sexual orientation and is often associated with a lack of political and social agency.⁵ Often viewed as microaggression,⁶ invisibility plagues higher education in many facets. Numerous scholars have contributed research exploring issues of invisibility in higher education based on race, ethnicity, gender, class, and sexual orientation amongst students, faculty, and staff. Disability invisibility is also an issue within higher education. Disability invisibility refers to “the absence of disability from the conversations and activities that establish the way a society functions, encompassing social relationships, intellectual and artistic work, and politics.”⁷ Significant consideration must be given to how higher education institutions and educators adopt and practice disability invisibility and the impact such systems have on disabled students, especially students with invisible disabilities. How does higher education promote and support the invisibility of the disabled? What disabilities are seen and recognized in higher education? Who is recognized as disabled in higher education? This paper explores how higher education has embraced historical practices of disability invisibility by adopting ableist practices that promote the exclusion of disabled learners.

Disability in Higher Education

Higher education continues to see an increase in the number of students enrolling with disabilities; since 2000, there has been a 2% increase in students' enrollment with disabilities.⁸ The importance of higher education to those with disabilities is well documented.⁹ As a result, legislation - Section 504 of Rehabilitation Act (1973), American with Disabilities Act (ADA; 1990), and ADA Amendments Act (2008) - has been put in place to make higher education more accessible for students with disabilities. Under ADA, agency is placed on learners to self-identify their disability and seek ‘reasonable’ accommodations. Accommodations are not always granted or upheld.¹⁰ Additionally, learners often struggle to identify disabilities, do not identify disabilities out of stigma, and do not always have the resources needed to get a proper

⁵ Susannah B Mintz, “Invisibility,” *Keywords for Disability Studies* no. 7 (2020).

⁶ Jasmine A Mena and Annemarie Vaccaro, “‘I’ve struggled, I’ve battled’: Invisibility microaggressions experienced by women of color at a predominantly White institution,” *NASPA Journal About Women in Higher Education* 10, no. 3 (2017): 301-318.

⁷ Mintz, “Invisibility,” 113.

⁸ Ehlinger and Ropers, “It’s All About Learning as a Community”; Yssel. Pak, and Beike, “A door must be opened.”

⁹ Dalia Sachs and Naomi Schreuer, “Inclusion of Students with Disabilities.”

¹⁰ Benjamin J. Lovett, Jason M. Nelson, and Will Lindstrom, “Documenting hidden disabilities in higher education: Analysis of recent guidance from the Association on Higher Education and Disability (AHEAD),” *Journal of Disability Policy Studies* 26, no. 1 (2015): 44-53.

diagnosis.¹⁰ Such struggles present educational barriers for students with disabilities, especially those with invisible disabilities.

Invisible Disabilities

Amongst students with disabilities are those with invisible disabilities. Invisible disabilities, also called hidden disabilities, "...refer to diseases, conditions, and sensations that cannot be observed externally, such as chronic pain, cognitive or psychiatric impairment, or Deafness."¹¹ Invisible disabilities may be medical, developmental, or cognitive and generally impact a person's body functioning or the way individuals think, act, speak, or interact with others. Examples of invisible disabilities include special learning disorders (SpLDs), ADHD, autism, diabetes, epilepsy, migraine headaches, and mental disorders.¹² Students with invisible disabilities face greater educational barriers to student success, seeing as their disabilities "present unique challenges in a society already prone to suspicion about the reality status of illness and provoked to anxiety by incapacity and pain."¹³ Despite growing in number, students with invisible disabilities are generally unrecognized by higher education professors and staff.¹⁴ Due to no notable physical disabilities, many students with invisible disabilities are viewed as having little barriers to student success,¹⁵ resulting in disability invisibility at multiple levels.

Disability Invisibility in Higher Education

Because disability often goes unrecognized and unseen, opinions are routinely made regarding student needs and abilities which often results in higher educators favoring ableism over inclusivity. Ableism is "the conscious and unconscious favouring of those perceived as 'able' over those perceived as disabled, or indeed those assessed as disabled."¹⁶ Assumptions regarding higher education learners' ability create deficits in inclusive pedagogical, instructional, and institutional practices. It is apparent that disability invisibility cultivates ableism and creates a power dynamic that results in the marginalization and oppression of

¹¹ Mintz, 113.

¹² Claire Barnett, "Disabled at Vanderbilt: Visible vs. Invisible Disabilities," *The Vanderbilt Hustler*, accessed March 28, 2021.

¹³ Mintz, 113.

¹⁴ Donna Couzens, Shiralee Poed, Mika Kataoka, Alicia Brandon, Judy Hartley, and Deb Keen, "Support for students with hidden disabilities in universities: A case study," *International Journal of Disability, Development and Education* 62, no. 1 (2015).

¹⁵ Halley Sutton, "Go beyond required accommodations for students with invisible disabilities," *Disability Compliance for Higher Education* 24, no. 6 (2019).

¹⁶ Shrehan Lynch and John Macklin, "Academic Ableism in Higher Education," *Birmingham City University Education Journal Magazine* 1, no. 1 (2020): 39.

disabled learners and shapes higher education practices and discourse.

Marginalization and Internalized Oppression

Disability is “one of the most frequently forgotten forms of social, political, and cultural oppression.”¹⁷ Disability invisibility cultivates ableism, which results in the increased marginalization and oppression of disabled learners in higher education. Ableism values ableness and enforces the stigma of the disabled. Therefore, students deemed as able-bodied are considered the “norm.” Disabled students are considered “abnormal or non-normative embodied minds” and met with prejudicial and negative attitudes from faculty and staff.¹⁸ It is recognized that they are not performing at the standard considered proficient for a postsecondary learner. Research substantiates that negative attitudes impact learners' success with disabilities and affect inclusion.¹⁹

Disability invisibility also results in internalized oppression for many disabled learners in higher education—internalized oppression results from exclusion, discriminatory attitudes, and social practices. “Internalized oppression arises when individuals within a marginalized constituency are led to accept the values of the dominant culture, thereby becoming complicit in their marginalization.”²⁰ Educators and institutional and instructional practices often leave disabled learners feeling invisible, like they cannot succeed and do not belong. A study conducted in 2018 explored how intersectional ableism shaped 13 physically disabled students' perceptions and experiences. All the participants experienced erasure based on the oppression of one or more identities. Some of the participants downplayed their disabilities to appear “normal” and as a means to navigate ableism. The experience took a drastic toll on the participants' energy, engagement, and overall well-being.²¹ Ultimately, marginalization and oppression take a negative toll on the learners and create barriers to academic success.

Higher Education Practices and Discourse

Higher education practices are shaped hierarchically, organizationally, and architecturally in

¹⁷ Lynch and Macklin, 39.

¹⁸ Hall, Melinda C., “Critical disability theory.”

¹⁹ Ehlinger and Ropers, “It’s All About Learning as a Community”; Sachs and Schreuer, “Inclusion of Students with Disabilities,” Sharlene A Kihara and Dixie S. Huefner, “Students with psychiatric disabilities in higher education settings.”

²⁰ Marsha Saxton, “Hard bodies: Exploring historical and cultural factors in disabled people’s participation in exercise; applying critical disability theory,” *Sport in Society* 21, no. 1 (2018): 26.

²¹ Ehlinger and Ropers, “It’s All About Learning as a Community.”

ways that reflect society.²² With disability invisibility being such a prominent practice in American history, it is no surprise that the tradition is noted in multiple facets of higher education practices and discourse. Institutional and instructional systems tend to cater to nondisabled learners. Nondisabled individuals are 40% more likely to attend higher education than disabled individuals.²³ Higher education students with disabilities are dropping out at a higher rate than their peers without disabilities; it is estimated that 34% of college students that identify as disabled complete a four-year program.²⁴ Students with psychiatric disabilities account for a substantial number of students with invisible disabilities, surpassing the number of students with learning disabilities and attention deficit disorder combined. It is noted that 86% of students with psychiatric disorders withdraw from college prior to completion.²⁵

Despite there being measures in place for accommodations and disability support, these tools only assist disabled students within reason. For instance, writing is a requirement for most college students. While many disabled students are provided accommodations that provide more time for testing, extended time for writing papers is generally not an accommodation granted to college students. This fact even applies to classes like Composition that use papers as assessments. Written work is valued in higher education because it shows intellectual ability.²⁶ With writing being such an integral component of student success, one would think that accommodations would be provided for disabled learners, especially those with invisible or cognitive learning disabilities, to have extended writing time. This is not the case, and instructors rarely adjust their curriculum with this point in mind. Additionally, the amount of reading and writing required of learners at a given time and stringent deadlines and timeframes are approached in a manner of “one-size fits all.” It is presumed that because a learner is in higher education, he or she can maintain the intense pace. Higher education falls under the beliefs of independence, autonomy, and individualism, the antithesis of the beliefs of disability. Griffiths²⁷ noted that the marked identity of a neoliberal citizen is a worker who is willing, capable, and able. In distinguishing between the willing, capable, and able, Griffiths²⁸ identifies capability as the capacity to learn, ability as contextual, temporal, and unclear, and willingness as what drives one to overcome barriers of capability and ability. Postsecondary learners are

²² Lynch and Macklin, “Academic Ableism in Higher Education.”

²³ Kirstein Rummery. From the personnel to the political: Ableism, activism, and academia. *Ableism in Academia: Theorizing experiences of disabilities and chronic illnesses in higher education*. UCL Press, 2020.

²⁴ Christa Bialka, “College students with disabilities are too often excluded,” *The Conversation* (2018).

²⁵ Kihara and Huefner, “Students with psychiatric disabilities in higher education settings.”

²⁶ Lynch and Macklin.

²⁷ Griffiths, “But you don’t look disabled.”

²⁸ Griffiths, 137.

often assumed willing, capable, and able to undertake the demands of higher education. Unlike primary and secondary education, higher education is deemed optional, and something learners choose to undergo. While autonomy and agency generally play integral roles in seeking higher education, learners are often in pursuit of opportunity, advancement, and a more significant way of life. Society places a tremendous amount of emphasis on credentialism and the need and merit of higher education for individuals, families, and society. “The labour market of higher education emphasises what Pinder refers to as ‘productivity and performance.’ We need to be always productive and always performing.”²⁹ The drawback to the idea of ‘productivity and performance’ is the assumption that higher education learners can perform and produce at the pace higher education demands. It is not that learners are not capable or willing; abilities vary amongst learners, especially amongst disabled learners. When disability is not viewed, recognized, or considered in higher education, expectations are not always realistic or feasible. As disabled scholar Elisabeth Griffiths notes, although willing and capable, sometimes disabled learners cannot perform to such intense standards. Griffiths states, “I want to feel welcomed and understood in academia, so that on days when I cannot ‘hyper-perform’ then it is OK to say ‘no more today,’ without it affecting my ambitions, prospects, collegiality, or sense of self.”²⁹ Disability invisibility and ableism in higher education create a space where many disabled students feel that hyper-performance or failure are their most feasible options.

Conclusion

Disability Invisibility presents challenges to inclusive educational practices for those who are viewed or identified as disabled in higher education. With the increasing number of students with disability enrolling in postsecondary education, efforts must be made to make instruction more accessible for all learners. Further consideration must be given to how much is ignored, unknown, and assumed about higher education learners and their abilities. Physical and invisible disabilities need to be recognized and not stigmatized. In changing the power dynamic and not making disabled students feel ostracized, excluded, and invisible, higher education can truly begin moving towards an equitable teaching model.

²⁹ Griffiths, 126.

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Utterances of Mourning and Loss: Appearances of Down Syndrome in Parenting Books

Madeleine DeWelles¹

Introduction

This paper understands perceptions of disability as social, historical, and cultural processes². I ask: *How do utterances of mourning and loss appear in parenting books directed to caregivers of children with Down syndrome?* I address this question in three ways. I provide a brief overview of how Down syndrome has historically been communicated to parents through words of loss and sorrow³. I then consider two parenting books—*Babies with Down Syndrome*⁴ and *When Down Syndrome and Autism Intersect: A guide to DS-ASD for Parents and Professionals*⁵. Although there has been important work that confronts ableist responses to the birth of a baby with Down syndrome, such as the Canadian Down Syndrome Society’s “Anything But Sorry” campaign⁶ and the photography book *Down Syndrome: A Whole New World of Perfect*⁷, words of sorrow may continue to appear. Ultimately, this paper demonstrates how utterances of sorrow after the birth of a baby with Down syndrome cement normative expectations of birth and parenthood. I reveal how, although we are in a world that seeks to include children with Down syndrome, we are also in a world where words of loss remain. Attending to such a contradiction is perhaps how we might think differently about disability, Down syndrome, and the expectations placed upon babies, children, parents, and their relations.

A history of Down syndrome, a history of sorrow

Over the course of my graduate studies, while I’ve maintained an interest in representations of Down syndrome in the news and in children’s storybooks, a newer interest is how sentiments of “I’m sorry” and/or sorrow appear in the lives of parents and children, mediating our relations

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² Tanya Titchkosky and Rod Michalko (eds), *Rethinking Normalcy: A Disability Studies Reader*. (Canada: Canadian Scholars’ Press, 2009).

³ Catherine McKercher, *Shut Away: When Down Syndrome was a Life Sentence* (Fredericton: Goose Lane Editions, 2019); Victoria Freeman, *A World Without Martha: A Memoir of Sisters, Disability, and Difference* (BC: Purich Books, 2019).

⁴ Susan J. Skallerup. (ed), *Babies with Down Syndrome: A New Parents’ Guide* (Bethesda: Woodbine House, 2008).

⁵ Margaret Froehlke and Robin Zaborek (eds), *When Down Syndrome and Autism Intersect: A Guide to DS-ASD for Parents and Professionals* (Bethesda: Woodbine House).

⁶ Canadian Down Syndrome Society. “Anything But Sorry”. n.d. <https://cdss.ca/awareness/anything-but-sorry/>

⁷ Trina Hoadley, *Down Syndrome: A Whole New World of Perfect* (Canada: Circle 21 and Trina Hoadley Photography, 2014).

to Down syndrome and to each other. This interest began about a year ago when I came across the Canadian Down Syndrome Society's *Anything But Sorry* campaign⁸, which is an anti-ableist awareness campaign. It demonstrates how the response of "I'm sorry", while still so common, is an inappropriate response to the birth of a baby with Down syndrome. The campaign features young adults with Down syndrome and their parents (mostly mothers), who discuss stories of how the "news" of having a baby with Down syndrome was "broken". Parents recall how an eerie sense of discomfort came across the delivery room, and the doctors would say "I'm sorry, but we think your son/daughter/child/the baby has Down syndrome"⁹.

In a past presentation, I have discussed how this campaign was very important because it positions the word "Sorry" as a swear word—as something that should never be uttered. This campaign, therefore, offers a necessary intervention into cultural and social responses to Down syndrome, to birth, to notions of the child, and to relations between the parent and child. So too do other campaigns and projects, including a beautiful photography book entitled *Down Syndrome: A whole new world of perfect*.¹⁰ This book displays photographs, taken by Trina Hoadley, of children, teenagers, and adults with Down syndrome, as well as words of love and affirmation from their parents. A central theme throughout this book is that children with Down syndrome are perfect in their own ways, and bring immense joys to the parents and families they are a part of. Additionally, bioethicist Chris Kaposy¹¹ uses memoirs and experience to show that having a child with Down syndrome *does* bring joy and love, despite historical and social assumptions. While the love that parents have for their children is so clearly displayed in this book, through memoirs, and through campaigns, we *still* live in a world where notions of sorrow exist in many ways. Sorrow is not only directed at children with Down syndrome. It is directed at parents. So too is there sorrow, regret, and disbelief at *responses of sorrow* to children with Down syndrome and their families. Sorrow, then, appears very much as part of the human condition¹². This is a difficult contradiction to come to terms with—and at times, it is an impossible contradiction and expectation that is placed directly within the relationship between a parent and a child. But this, I believe, is why it is so crucial to attend to.

⁸ Canadian Down Syndrome Society, "Anything But Sorry," n.d. <https://cdss.ca/awareness/anything-but-sorry/>

⁹ "Anything But Sorry."

¹⁰ Trina Hoadley, *Down Syndrome: A Whole New World of Perfect* (Canada: Circle 21 and Trina Hoadley Photography, 2014).

¹¹ Chris Kaposy, *Choosing Down Syndrome: Ethics and New Prenatal Testing Technologies* (MIT Press, 2018).

¹² Hannah Arendt, *The Human Condition, Second Edition* (Chicago: University of Chicago Press, 1998).

Institutionalization: A response to sorrow

Institutions for intellectually disabled people in Ontario—Hurononia in particular—have faced lawsuits with regard to the inhumane and dehumanizing treatment that residents (prisoners) faced within these centres. And it is this treatment that society is now sorry for, *even as these institutions were originally created as a response to the sorrow felt after a baby was born with Down syndrome*. So, why institutionalization? Why was it considered “the best place” for young children—babies even—with Down syndrome?

According to Catherine McKercher¹³ and historian David Wright,¹⁴ until about the early nineteenth century, people with developmental disabilities were considered uneducable. However, this changed through the work of French physician, Dr Jean Marc Gaspard Itard, who took in a young child who was called the Wild Boy of Aveyron into his home and apparently the child “made excellent progress” with Itard. This case set the scene for a peculiar kind of “hope” that children with intellectual disabilities like Down syndrome could and should be educated. Institutions were like beautiful boarding schools, which was especially the case in the United States where students would spend 10 months of the year in school, and then have the summers off—much like how schools and education function in Western contexts today¹⁵. As McKercher notes, one of the first “boarding schools” that operated in such “idyllic” ways opened its doors in Barre, Massachusetts in 1848, “... at the private home of Dr Hervey B. Wilbur”¹⁶. Additionally, McKercher notes, “The schools brought children in at a young age, pushed them to develop to their full potential, and then sent them back home when they reached a maximum age, typically sixteen. Once back in their communities, the children would, presumably, live full and rich lives”¹⁷. But even these schools were structured around so many exclusions—the schools had strict admissions criteria where those deemed “too severe” would not be welcomed. Even within a school that was presumably created for those children excluded from mainstream schooling, so many exclusions existed within its walls.

This sort of organizational structure of the education/institutional system also represented a kind of “hope” that children with Down syndrome and intellectual disabilities could integrate

¹³ Catherine McKercher, *Shut Away: When Down Syndrome was a Life Sentence*. (Fredericton: Goose Lane Editions, 2019).

¹⁴ David Wright, *Downs: The History of a Disability*. (Oxford University Press, 2011).

¹⁵ McKercher, *Shut Away*, 47.

¹⁶ *Ibid.*

¹⁷ *Ibid.*

back into the community and be “productive members” of society. This, however, was not the case. As children grew up, school officials recognized that children with Down syndrome would not develop to societal expectations of productivity and intellect. Rather, they would need constant and consistent, year-round care, for their entire lives. As such, the structure of residential institutions came to be, and the horrific mistreatment that resulted from them.

Turning now to a specific Ontario-based example, consider Huronia, or what was originally called the Orillia Asylum for Idiots, which opened in 1876¹⁸. Prisoners at Huronia were subject not only to abuse, but to a wide range of psychiatric testing, diagnosis, control, and discipline. Testimonies from survivors are horrific, documenting abuse, neglect, and mistreatment. Of particular interest for my own research are the memoirs that have been written by siblings of children who were sent to Huronia and the Rideau Regional Centre (based in Ottawa, Ontario). These include *A World Without Martha* by Victoria Freeman and *Shut Away: When Down syndrome was a life sentence* by Catherine McKercher. The testimonies of survivors and their families demonstrate the horrible ways that people with intellectual disabilities were deprived of love, care, and dignity. For example, the Remember Every Name survivors’ initiative is dedicated to remembering and memorializing the survivors who died—or killed—supposedly in the “care” of these institutions¹⁹. It is incredible, then, that at a point in our not-so-distant history, institutions were a response to the sorrow that families felt upon receiving a diagnosis of Down syndrome. Yet, sorrow remains – the sorrow and regret for what occurred at these institutions haunts us. These institutions were never a remedy for sorrow, but rather, sustained and perpetuated it.

Contemporary Utterances of Sorrow and “I’m Sorry”

Having provided a very brief overview of institutionalization and the sorrow that haunts its history, I turn now to more contemporary utterances of “I’m sorry”—which are, at times, hidden in unexpected places—such as parenting books.

The question of parenting is a fascinating one. The worlds of parents and children are tethered to one another and many books exist that demonstrate, show, or guide parents towards particular understandings of what it means to raise a child *and* what it means to be with a child—

¹⁸ Jen Rinaldi and Kate Rossiter, “Huronia’s Double Bind: How Institutionalisation Bears Out on the Body,” *Somatechnics* 11, no. 1 (2021): 92–111.

¹⁹ “Who We Are,” Remember Every Name, 2022, <https://www.remembereveryname.ca/>

to support them, to love, and nurture them. Consider, for instance, the iconic *What to Expect When You're Expecting*²⁰ or *What to Expect: The first year*²¹. And while this is important, the mere existence of parenting books illustrates that how one's child "turns out" is in direct relation to how one parents or conceives of themselves *as a parent*. Returning to the title *What to Expect When You're Expecting*, there are already expectations placed on both child and parent *before birth*. But then, what happens when you *do not* expect something. What happens when a child is *unexpected*?

Parenting Books and Hidden Sorrows

*Babies with Down syndrome, Third Edition*²² is a guide for new and prospective parents of babies with Down syndrome. There are numerous endorsements on the back of the book, praising it for its content, facts, developmental and medical information, and more. And while the book works towards dispelling ableist stereotypes, myths, and assumptions about Down syndrome, there are various ways that sorrow, and even notions of "I'm sorry" appear in this book.

Babies with Down Syndrome opens with the following" "If you are like most people, you probably had little understanding of what Down syndrome meant before your baby was diagnosed"²³. From this quotation, there is a *big* understanding that you (a parent) have *little* understanding about Down syndrome until your baby is born—until you are touched by one of the closest and most intimate relationships—the one between a parent and a child. Interestingly, *Babies with Down syndrome* appears somewhat as an intermediary within this most delicate and intimate relationship. The book goes on to then provide scientific explanations of how Down syndrome is caused on a cellular, genetic basis. It also discusses the physical characteristics and features of babies and children with Down syndrome. It also discusses prenatal testing. The book speculates that you [the parent] might have received a prenatal diagnosis, or your doctor might have suggested a prenatal test through amniocentesis, or you might be considering prenatal testing. Now, beyond factual accounts of what the tests will show, there are also testimonies of parents scattered throughout the book, including in this section on

²⁰ Heidi Murkoff, *What to Expect When You're Expecting, Fifth Edition* (New York: Workman Publishing Co., 2016).

²¹ Murkoff and Mazel. *What to Expect*.

²² Susan J. Skallerup (ed), *Babies with Down Syndrome: A New Parents' Guide, Third Edition* (Bethesda: Woodbine House, 2008).

²³ Skallerup, *Babies with Down Syndrome*, 2.

prenatal screening. All of these testimonies, in some shape or form, are tinged with a sense of sorrow, not always or exclusively about the baby with Down syndrome, but about the responses (i.e. *being sorry about the sorrow* that may follow a baby with Down syndrome). The following testimonies are from parents who received a prenatal diagnosis of Down syndrome. To begin, one parent recalls:

After Hope [child's name] was born with Down syndrome, a few people had initial reactions along the lines of, 'Oh, so you didn't have prenatal testing?' The implication was that we wouldn't have had our baby if we'd known in advance. I thought that was incredibly rude to imply²⁴.

Another parent states:

After we got the prenatal diagnosis, we felt a lot of pressure from the doctor to make up our minds quickly—when in reality, we had weeks to decide whether to keep our baby. It was almost as if the doctor didn't want us to have time to think. He told us several times how many parents decide to 'terminate'—as if that should be the deciding factor for us. When I think about everything we would have lost out on if we had listened to this ignoramus tell us what to think, I still get all shaky inside.²⁵

Within these two quotations, much is revealed not only about parenting and childhood, but about the social, cultural, medical, and historical surroundings that make these possible. The above two quotations in particular reveal the intersections of medicine and parenthood, as also illustrated in Gareth Thomas's ethnography of a UK-based prenatal clinic²⁶. The amniocentesis, a medical test, can be used for parents as a way to prepare them more for the unexpected. No parent knows what their child will be, or who their child may become. And no parent knows what goes on beneath the layers of skin, muscle, and fat that house the fetus or baby within the uterus. The amniocentesis is a window into this world of unknown – it helps make this world a little bit *more* known. As Rayna Rapp says, prenatal testing has "revolutionized pregnancy"²⁷—but with this revolution, we must take care and caution. Following Rapp and her discussion of how prenatal testing straddles the worlds of eugenics and liberatory knowledge, how do we grapple with the potentially negative, jarring, or insulting consequences, demonstrated by the doctor who "pressured" the parents to make a decision, who said that many parents choose to

²⁴ Skallerup, 40.

²⁵ Ibid. 41

²⁶ Gareth Thomas, *Down's Syndrome Screening and Reproductive Politics: Care, Choice, and Disability in the Prenatal Clinic* (United Kingdom: Taylor and Francis, 2017).

²⁷ Rayna Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (New York: Routledge, 2000), 11.

terminate a baby with Down syndrome? Similarly, we see the others who assume that a baby with Down syndrome would be kept because the parents *did not* have prenatal testing and, therefore, did not *know* about a diagnosis of Down syndrome.

Sorrow appears here too, but in less obvious ways. Consider the doctor who tells the parents about how many people terminate; consider the parents and friends who think that termination would be the expected—even necessary—response to finding out a baby has Down syndrome. These are other ways of shaping or packaging sorrow, surprise, and confusion. Moreover, these testimonies themselves can also be read as a *response* to sorrow. These testimonies appear almost as apologies for the “backwards” attitudes or “insulting remarks” or even the “ignoramus” doctor. These testimonies are *sorry for sorrow*. Recall the second quotation, where the parent said, “When I think about everything we would have lost out on if we had listened to this ignoramus tell us what to think, I still get all shaky inside”²⁸. Here, sorrow and loss is *projected*, placed into what are imagined to be sorrowful and regretful parents. But nevertheless, sorrow remains. Consider one final example, which bears crucial ties to institutionalization as well.

Right after playwright Arthur Miller died in 2007²⁹, I read an article that revealed how he’d had a child with Down syndrome but never publicly acknowledged him. In fact, Miller put his son in an institution and rarely saw him...So, even though we’re now in the twenty-first century, there are still ordinary people—even quite well-educated ones!—walking around with terrible backwards ideas about Down syndrome. It’s really shocking.³⁰

Here, we see another connection to the sorrow for the horrors of institutionalization. But also, we see sorrow for the parental decision that Arthur Miller made. Others have made similar observations. For instance, in an article by USA Today, scathing claims are made about the moral pitfall of Arthur Miller³¹. How could a man who wrote so perceptively about the human condition abandon his son with Down syndrome in an institution?

²⁸ Skallerup, 41.

²⁹ This is a factual error. Arthur Miller died in 2005 (The New York Times 2005).

The New York Times. “Arthur Miller, Legendary American Playwright, is Dead”. 2005, February 5.

<https://www.nytimes.com/2005/02/11/theater/arthur-miller-legendary-american-playwright-is-dead.html>

³⁰ Skallerup, 40-41

³¹ Steve Tisch, “Arthur Miller failed a profound moral test. What should we now think of his plays?” *USA Today*. June 25, 2018, <https://www.usatoday.com/story/opinion/2018/06/25/arthur-millers-down-syndrome-son-tarnishes-moral-artistic-legacy-column/725003002/>

In all of these cases, sorrow exists, but takes on a different form. Sorrow is not directed towards a baby with Down syndrome. Rather, the sorrow expressed is almost exclusively about the medical and social conditions that surround parenthood, or the decisions that parents might make. The response, then, of “I’m sorry” is far more complicated than it may seem. Sorrow cannot be individualized. It has a deep medical, social, and historical context that shape notions of not only children, but of the relationship that parents and children might have.

Parenting Books and Not-So-Hidden Sorrows

While my brief discussion of *Babies with Down syndrome* illustrates the intricacies and nuances of expressions of sorrow, there are other, far more obvious, representations of sorrow in parenting books as well. Consider, for instance, *When Down Syndrome and Autism Intersect*³². This book straddles hope and despair, telling parents that Down syndrome and Autism are increasingly being co-diagnosed, and that, with the necessary interventions, parents should not worry. Now, the emphasis on hope and the reassurance that appears in this book (and to a large extent, *Babies with Down syndrome* as well), such reassurance would not exist if there was not an assumption of sorrow, shock, fear, or worry. This assumption is directly expressed in *When Down syndrome and autism intersect*. In chapter two, entitled “But I was Just Getting Used to Holland”³³, there is a long section on “common emotions”, one of which is “Chronic Sorrow”. The passage says:

Much has been written about the experiences of parents whose children have developmental disabilities...In general, however, there are two main ideas presented about this experience. The first is that parents have a grief reaction that progresses through various stages over time... The second significant idea, called chronic sorrow...is that parents will experience periods of time when the intense grieving reoccurs and that these periods may go on indefinitely. In other words, there is no real end point.³⁴

³² Sarah A Hartway, “But I was Just Getting Used to Holland: Adjusting to the Autism Diagnosis,” in *When Down Syndrome and Autism Intersect: A Guide to DS-ASD for Parents and Professionals*, edited by Margaret Froehlke and Robin Zaborek (Bethesda: Woodbine House, 2013).

³³ The reference to Holland is based on a paper written by Emily Kingsley, writer and producer of *Sesame Street*, and whose son has Down syndrome. “Welcome to Holland” is about arriving at a destination, a parenting destination, that might not be expected, but is joyful and fulfilling (Kingsley 1987). The paper demonstrates the expectations of parents and children, and how sorrow, loss, and grief appear when these expectations are disturbed or disrupted. Kingsley, Emily Perl. “Welcome to Holland,” 1987. https://www.dsasc.ca/uploads/8/5/3/9/8539131/welcome_to_holland.pdf

³⁴ Margaret Froehlke and Robin Zaborek (eds.), *When Down Syndrome and Autism Intersect: A Guide to DS-ASD For Parents and Professionals* (Bethesda, Woodbine House, 2013), 15.

The passage also mentions the work of Simon Olshansky who first described the “chronic sorrow theory.” This theory states that parents of “mentally defective children” often experience “chronic sorrow,” which is an ongoing sorrow and exists whether the child is in the home or “put away” (a euphemism for institutionalized)³⁵.

This notion of chronic sorrow adds to the complexity of the present discussion. The notion of “chronic sorrow” may be something to be sorry for—there is a feeling of discomfort with this idea. Going back to the Canadian Down Syndrome Association’s “Anything But Sorry” campaign, chronic sorrow surpasses the immediate response of “I’m sorry” after a baby’s birth, and instead, illustrates how sorrow follows parents and children throughout their lives. Moreover, according to Olshansky, sorrow remains, even when a child is “put away” or institutionalized. This highlights how institutionalization *still generates sorrow*. This sorrow is largely generated as a result of the disruption of normalcy. Down syndrome disrupts normative demands on parents and children—such as what the child “should be or do”. The ideal of the child (and by extension, the parent) is disturbed and disrupted. And as a result, Down syndrome is blamed. Grief is generated not as a result of Down syndrome, but as a result of a perceived broken expectation—a broken contract between a parent and child that the parent will nurture and guide the child towards independence, productivity, and conventional, Western notions of success. This theory of chronic sorrow, as troubling as it is, demonstrates how sorrow remains in subtle and obvious ways, ways that show how sorrow is generated where normalcy is disrupted, even where campaigns exist to stop it.

A World of Contradictions

At its core, this paper illustrates how words and sentiments of sorrow surround the relations that parents and children have with each other. The particular response of “I’m sorry” and the more general sentiment of sorrow are indicative of the ways in which children “should and could” be. Down syndrome, when it appears in the midst of a parent-child relationship, is so often responded to with sorrow. As I have demonstrated, sorrow never appears in a vacuum. Rather, sorrow is historically, medically, and socially informed, and it mediates our relations within and between children, parents, disability, and each other. Rather than pushing sorrow away, however, I contend that it is an important entry point into revealing how sorrow is so

³⁵ Simon Olshansky, “Chronic Sorrow: A Response to Having a Mentally Defective Child,” *Social Casework* 43, no. 4 (1962): 190–93.

often generated as a response when normative, Western-centric ideals of independence, productivity, and success are disrupted. Through sorrow, however, we also gain entry into deeper understandings into what characterizes the relationship between children, parents, disability—and the question, but also the strength, of love.

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A Fat Teacher's Manifesto: Introduction to Fat-Informed Compassion-Based Teaching

Olivia DiGiammarino¹

Most simply put, fat kids are vulnerable. They are targets of bullying, examples of failed parenting, cause for national campaigns to fight obesity and underestimated by both peers and teachers within the education system. I've lived and continue to live this experience. I was a fat kid, who became a fat adult who is now a fat teacher. I remember the embarrassment of not fitting into school uniforms, being taunted and habitually made to feel invisible. Now, I watch my fat students squeeze themselves into rigid desks with attached chairs that fail to legitimize body- diversity. Like the desks, not much has changed.

I have a soft spot for fat students, because fatness as both state of being and identity is so misunderstood and yet so readily subjected to advice, diets, exercise routines and self-hatred. Fat-kids are made to think that their vulnerability is an earned consequence to self-inflicted fatness. We should acknowledge that Physical Education, like all of education, has roots in oppression (Freire, 1970) but we must stand fervent to the reality that it continues to exploit fat-children. As Pause writes "I believe this is the key damage done to fat kids in physical education; we are taught, from an early age, that the only purpose of exercise for us is weight loss. It is not about enjoyment or finding pleasure in the things our bodies can do" (p. 666). If we look to pre-service teacher training, additional qualifications or professional development, fat-pedagogy remains on the fringe of Physical Education and students continue to be codified according to their bodies.

This paper will propose how the medical model of disability within education creates punitive and disciplinary systems for fat students. We will explore how the Ontario Physical Education system subjugates fat bodies, drawing on language used within curriculum and policy in Ontario to support the medical model of disability. Lastly this paper will turn to my own experience as a fat-kid, now fat-teacher, and how fat-informed compassion-based teaching could potentially change how teachers and students approach Physical Education.

Physical Education and the Medical Model

When thinking about the broad spectrum of Physical Education there is often focus on the holistic gains a typical student would experience. Moments of leadership, skill building and

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character development. All of these skills and lessons are important, nuanced and often not well integrated in a traditional classroom. Despite these potential gains, we need to consider the ethics of a course centered on physical ability. Specifically how non-disability is seen as a prerequisite to participation. The assumption of non-disability reinforced by Physical Education, permeates school culture and can cause irreparable social, emotional and psychological damage during a time of rapid physical transition from childhood through puberty to adolescence. The medical model of disability according to Oliver (1990), identifies this understanding of disability as the medically identified impairment or deviation from a medical standard and non-impaired body. Due to the medical industry's proclivity to quantify bodies using weight and measurements, the body is easily limited to a numerical composition (Stoll, 2019). Ultimately lending this data to averages, standards and deviations. Guided by these principles, Physical Education has long been influenced by medical processes and are predisposed to quantify, categorize and regulate bodies.

The regulation of bodies occurs incrementally and often invisibly in the earliest of elementary classrooms. Imagine a class of junior kindergarten students learning how to sit on a carpet, or being told to keep their hands to themselves. These behaviours have been normalized for the sake of classroom management, order and control. However, practicing and performing compliance in these small and seemingly insignificant ways, primes students for long term regulation and behaviour modification.

Therefore, we must scrutinize the minutia of Physical Education as a location of the medical model of disability and as an extension of performed compliance. In *Health Education Journal*, (*Can we get together? Fat kids and physical education*), Cat Pause writes poignantly about systematically oppressive Physical Education classes. Pause cites their own experiences to illustrate the damaging legacy of Physical Education, "Physical education in compulsory schooling has long been criticised for being a site of normative healthism, portraying the idea that health is a controllable state by each individual and that each individual has a moral obligation to be in good health" (p. 665). What we glean from Pause (2019) is that Physical Education teachers that ascribe to the medical model of disability inevitably promote movement as weight-loss, and create environments limited to non-disabled bodies, all to be considered an active form of violence against fat-students.

The medical model of disability is located within the language of Physical Education. According to the Ontario curriculum, the Grade 9 Physical Education course PPL10, is entitled

“Healthy Active Living Education”. What value do we ascribe to the words *healthy*, and *active*? Prior to beginning the course, we have now identified that a student can learn to be healthy and learn to be active. These definitions are static, and influenced by medical guidelines for eating and activity. This openly invites the medical model perspective and governance over these terms and participants. When the term *healthy* is utilized as an objective, language is weaponized against fat-students and Physical Education becomes a location for the medical model of disability to define and confine bodies.

More importantly, what the medical model offers to Physical Education is a binary understanding of the body . There is a “good body” and a “bad body” (Stoll, 2019). The goal of Physical Education is to teach students how to maintain a “good body” or how to reform a “bad body”. This reformation is justified discipline, “people’s experiences of being publicly weighed exemplify how fat phobia strives to discipline the “unhealthy” fat body” (Sykes et. al, 2008, p. 67). Disciplining a fat-body can take several forms including, fat-shaming by a teacher, isolation from peer groups, public humiliation or encouraged disordered eating. All while under the guise of encouraging *health* or *fitness*. In the Journal for European Physical Education Review, Carmona-M’arquez et. al. discuss the impact of anti-fat bias and power dynamics of teachers and fat-students. In *Anti-fat bias in secondary school teachers: Are physical education teachers more biased than mathematics teachers?*, the culpability of teachers’ is explored and frankly heartbreaking;

Neumark-Sztainer et. al. (1999), for example, found that approximately a quarter of highschool teachers surveyed held the belief that obese people were more impulsive, less organized, and had more family problems than non-obese people. In the same study, 28% of teachers felt that becoming obese is the worst thing that could happen to a person. When the perspective of the potential victims of these discriminatory acts was investigated, it was found that 27% of a sample of adolescents undergoing treatment to lose weight claimed to have been victimized by their own teachers (Puhl et. al., 2013, 2).

This research is central to understanding the significance of victimization of fat-students by teachers because it has so often been understood as just and deserved and is ultimately informed by the medical model of fatness. Sykes and McPhail (2008) explore anti-fat bias and fat-phobia in physical education in *Memorable Lessons: Contesting Fat-Phobia in Physical Education*, legitimizing the experience and victimization of fat-students;

Generally speaking, however, fat people’s memories of physical education at school illustrate

how fat phobia created extremely difficult situations that demanded constant psychic/emotional work, provided pitiful opportunities for learning, and numerous alienating and traumatic movement experiences (67-68).

Anti-fat bias upheld by any subject teacher creates a barrier to equitable teaching standards and should be considered discrimination. However, the system of discipline against fat-bodies in Physical Education is layered to either cure the body from its deviance or discourage fat-students from participating, demonstrating failure to conform and ultimately exemplifying failure of fat-bodies. Turning to Carmona-M'arquez et. al. (2020);

... since many of the instances of victimization suffered by overweight youngsters occur in the context of PE [Physical Education] classes, it is likely that those who experience these episodes of discrimination may acquire an aversion to PA [Physical Activity], which may subsequently decrease their enjoyment of and motivation to take physical exercise (4).

A Physical Education environment informed by the medical model of disability means fat-students learn that the inaccessibility of Physical Education is due to the fault of, or fatness of, the participant. It is therefore up to the student to lose weight to change their experience, rather than Physical Education teachers, policy and curriculum becoming more accessible. This tactic is used to successfully propagate a hierarchy of bodies and reflect the medical model of disability.

Curriculum that Supports Anti-fat Bias & the Medical Model of Disability

In the article, "You are just an idiot for not doing any physical activity now": Health and Physical Education teachers' constructions of fatness (2016)," Vrea and Underwood study pre-service Health and Physical Education teachers, fat-phobia and the impact of anti-fat bias on fat students. Their findings reveal that pre-service Health and Physical Education teachers hold complex biases against fat-students. These biases are deeply entrenched in societal norms and are deeply connected to paternalistic structures and moral judgements of the body,

The construction of fat as achieved deviance led participants to employ discourses of morality in their discussions of bodies. For example, Judith stated that she was 'a little repulsed by people that are overweight'. She also stated that she did not know 'why most people can't actually have a decent body'. Through this statement, Judith implied that there is also an indecent body.... The fat body is marked as the 'other and deviant' body and the non-fat body is normalized. Most of the participants constructed discourses associated with fat bodies being disgusting or repulsive (472).

As we understand that Physical Education teachers may be predisposed to anti-fat bias, curriculum is not used to reform these concepts, but is used to justify the discrimination of fatness. The *Ontario Health & Physical Education Grades 9-12 (2015)* curriculum document uses the word ‘obese’ seven times including a working definition and suggested teacher prompts. One teacher prompt is as follows “...Being overweight or obese is a contributing factor for many common chronic diseases, such as diabetes or cardiovascular diseases. Being underweight also has significant health consequences.”(p. 96). The term *consequences* is a microaggression towards deviant bodies. A seemingly innocuous word reveals subconscious correlation between weight and diagnoses. In writing about the language of fatness, *Fat Invisibility, Fat Hate: Towards a Progressive Pedagogy of Size*, Tracy Royce (2016) examines the power of words used to describe fatness, “these “O words” work to establish larger bodies as unacceptably non-normative and in need of remediation (p. 24). To this effect, the suggested teacher prompt is followed by a suggested lesson on Body Mass Index, a system of measuring bodies based on height and weight; another example of the influence of the medical model of disability. This language does not invite inclusion, but rather maintains a binary system; healthy vs. unhealthy, able vs. disabled, fit vs. fat. Clearly, teachers reading these documents are not equipped to understand the nuance of teaching fat-students if the suggested prompt is to have their students calculate their BMIs. This is just one example of how curriculum documents actively work against fat-students, by allowing teachers to maintain a medical model approach to bodies and movement, locating the disability within the body and holding the individual responsible for achieving a state of cure.

The update to the *Ontario Health & Physical Education Grades 1-8 (2019)* curriculum included language identifying “determinants of health” to include “... income and social status, education and literacy, gender, culture, physical environments, social supports and coping skills, and access to health services” (pg.4), which impacts not only a student’s wellness and health but also their learning. This feels like progress towards a more holistic and intersectional approach to health. However, there is contradictory language used throughout the curriculum. For example, ‘Healthy Eating’ is the first key topic, beginning in Grade 1. By Grade 7, the curriculum expectation cites D2.1 as ‘Eating Patterns and Health Problems’,

Healthy Eating D2.1 demonstrate the ability to develop healthier eating patterns, using information about the role that different foods play as contributing or preventive factors in a variety of health disorders (e.g., cancer, Type 2 diabetes, cardiovascular disease, obesity, food allergies and anaphylaxis, tooth decay, osteoporosis; 257).

Utilizing the lens of Critical Disability Studies, there is a lot to unpack in these curriculum expectations. Firstly, healthy eating is subjective and access to food is not considered an identified “determinant of health”. This assumes that students have access to all foods, but specifically that their choices are divorced from their caretakers and guardians. In the discussion of preferred foods or ideal choices, we can draw an understanding that curriculum justifies moral judgment. In *Critical Pedagogical Strategies to Disrupt Weight Bias in School*, ‘choice’ is dissected by Pringle and Powell to reveal underlying power imbalances found in the subtle categorization of good vs. bad, “the moral imperative for individuals to make wise or sensible choices (i.e., those choices that will not lead to being unhealthy or fat) conversely intimated that fat people made “unwise” choices.” (p. 125). The lesson travels beyond a student’s personal connection. They have learned that a binary action such as choice-making is associated with physical implications. Therefore, non-fat students are now equipped to morally judge their fat-peers, while fat-students are equipped to continually judge themselves most likely without enough independence or agency to actually influence their choices. This kind of “learning” is intended to prevent children from becoming fat (Pringle, Powell, 2016). We must acknowledge that fatness, linked to disease, inactive lifestyles and unproductivity, allow fatness to consistently be promoted as deviance and transgression.

In 2017, the Ministry of Education in Ontario adopted Policy No. 138 entitled “Daily Physical Activity in Schools Grades 1-8”. This document is carefully worded and uses language that insists that daily physical activity as an attempt to increase productivity and academic success, “It can have a positive impact on their physical fitness and help lay the foundation for healthy, productive lives” (p.1). This policy does not outline or describe other facets of a healthy and productive life, other than to insinuate that if physical activity is not part of it there is a deficit in quality of life and productivity. Therefore, it is solidified through Policy No. 138, that physical activity can be prescriptive to ensure productivity, valuing homogeneity and calling it “health”.

Fat-Kid, Now Fat Teacher

My experience as a fat-kid was echoed in many of the academic articles referenced throughout this paper. Like many fat-students, I loved movement until it was organized and measured by a teacher. In high school after many failed diets I began a medically supervised ketosis that severely restricted my eating. When I could no longer sustain the diet, I gained twice the amount of weight I had lost. I had been indoctrinated to hate my fat body, which made caring for it into

adulthood even more challenging.

When I began teaching ten years later, I weighed over 355 lbs. I was on the waitlist at Humber River Hospital for a gastric bypass surgery and told people I was tired of being fat. Looking back on it now, I was tired of being oppressed. Most public environments weren't designed for people my size, I was afraid of getting bigger and I was deeply ashamed. I deeply resonate with Lesleigh Owen's writing *Fatness in a Thin World* (2012) as she describes the fat experience, "It is difficult to move through one's life, literally navigating spaces designed for the health, safety, and comfort of other persons, other bodies. As many disabled persons could attest, not fitting into the physical world carries with it many messages, all of them painful" (294). Gastric Bypass worked for me and resulted in a weight loss of over 125 lbs. Despite the weight I have lost, I have gained great insight and have healed from self-hatred. The process required me to once again lean into medical weight management and to my surprise it was delicately intersectional and surprisingly human. At the Bariatric Center at Humber River Hospital, I was never made to feel as if fatness was simple, or as if my inability to lose weight without the surgery was a personal failure. I was offered compassion and understanding and for the first time in a medical setting felt seen as a person, not solely as fat. Not to say that this experience of nuanced understanding in bariatric medicine is universal, but it was mine.

This has led me to what I consider to be fat-informed compassion-based teaching. For this paper, *compassion* must be divorced from pity in its traditional definition and should be understood as an intersectional and willingness to understand another person's lived experience including but not limited to trauma and pain, working to inform adequate and equitable service to legitimize their needs.

Fat-informed compassion-based teaching requires the following practices: (1) the teacher must acknowledge that fat-students are vulnerable and often discriminated against by peers and people in authority including teachers, (2) the teacher uses compassion as a modality of connection and equity in place of discipline (3) the teacher encourages students to advocate for themselves using the social model of disability. There is no requirement for a fat-informed compassion-based teacher to be fat or to identify as fat.

Lastly, in order for Physical Education to be reformed it requires fat-people to lend their voices, experiences and to enter a space that is not necessarily safe for fat-people and may very well reignite trauma. However painful, Pause (2019) reminds us of the importance of the fat

experience “Although policy, conversation and practice are often about fatness, what is largely missing are the voices of fat people. This is true in places of policy-making, media-making and science. Most research centers on medical frameworks of obesity, positioning the fat person as diseased, deviant and a problem to be solved.” (p.663). This is how fat-informed compassion based teaching can work for fat and other vulnerable students, but can also be extended to non-fat teachers, who do not have experiences from which to draw fat-informed compassion. Secondly, if we value compassion as a modality for connection by utilizing more fat-narratives, we can engage in teaching practices that are less focused on the homogeneity of students and the discipline of deviance. The last practice to incorporate the social model of disability is to disrupt the binary approach of the medical model. By encouraging students to draw on the discourse of the social model of discipline we are in many ways enacting Paulo Freire’s ‘questioning’ model of teaching (Freire, 1970) and engaging students not from an omnipotent and authoritative “knowing” but from an intersectional, compassionate curiosity. Perhaps in freeing our students' minds by challenging the medical model of disability, challenging exclusive curriculum and oppressive policy, we also free their bodies.

In closing, we have explored the tender experience of being a fat-student in the education system. A system that neglects, ignores and disciplines deviant bodies, justified by the promise of creating *healthy* and *productive* adults. We have also acknowledged that anti-fat bias is rampant within school culture as more fat people speak out about the trauma they have endured through Health & Physical Education classes. By centering these stories we can embrace fat-informed compassion based teaching that works to legitimize the experiences of fat students, challenge the intention and practice of Ontario curriculum documents and policy and engage students in authentic self-actualization, free from self-hatred.

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Perspective: Embracing and Highlight Disability Viewpoints through Artistic Undertakings

Molly Joyce¹ and Sandy Guttman²

“Disabled bodies are a repository for social anxieties about such troubling concerns as vulnerability, control, and identity.”

— Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*

“Disability is simultaneously real, tangible, physical, yet also an imaginative creation whose purpose is to make sense of the diversity of human morphology, capability, and behavior.”

— Joseph Straus, *Extraordinary Measures: Disability in Music*

Perspective is a sound, video, and research project featuring contributions from disabled participants worldwide; asking what disability-specific terms such as access, care, interdependence, and more mean to them. The work focuses on access as aesthetic, including aural playback of participant voices, open captions of their answers, and in the future haptic facets to feel vibrations of the music and more experimental processes to be developed. This multi-sensory focus represents a cross-disciplinary intersection of values from disability culture and justice such as access and interdependence, along with experimentation and adaptability in artistic forms for medium and accessibility.

The project symbolizes a progression of my artistic practice from a music-based background to substantial physical, experiential, visual, and social considerations all in pursuit of disability as a creative source and access as aesthetic. Through this development I hope to significantly advance my practice in collaboration with project contributors ranging the disabled interviewees, artistic collaborators, and more while providing tangible artistic and research outcomes.

Research questions to be explored include:

1. To what extent can values from disability culture such as access, care, control, and more serve greater solidarity, understanding, and organic communal engagement?

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- A detailed look at various approaches and processes to foster communal artistic engagement through questions based on individual yet societal experiences, yet specifically informed by disability culture. All project participants and students will contribute to such, allowing greater inclusivity and accessibility in project conception, production, and presentation.
2. How does accessibility as aesthetic form new artistic mediums for multi-sensory processes and outputs?
 - Investigation across aural, visual, tactile and further facets to redefine artist and audience sensory assumptions about artistic experience, opening up opportunities for creative output that are not based in traditional processes and assumptions about artistic production and presentation.
 3. How does placing disability first in an artistic work allow it to be viewed as a creative source rather than something to be discarded, inspirational, and/or overcome?
 - An exploration of how disability as the grounding for a new work creates its own aesthetic and goes beyond common comparative tropes of disability as a facet to be overcome and/or inspired by.

The desire for such a project comes from a dialogue with legendary activist Judith Heumann, who asked why I refer to my left hand as “weak.” My left hand was nearly amputated in a car accident twenty years ago, and it took almost twenty years for me to identify as disabled and embrace it. In spite of my personal evolution, I continued to refer to my disability as a “weakness” and categorize it within narrowly-defined social constructions of what weakness can and should be. Therefore with Heumann’s question I wondered if rethinking this terminology beyond such limited descriptions could allow broader understanding and interpretation of these terms while gaining a greater appreciation of and solidarity with disabled perspectives overall. I aimed to explore if such could be done by asking what these terms mean to disabled colleagues with varying impairments and experiences, in efforts to reframe collective perceptions about the lived reality of disability and build capacity for self-determination and overall social progress. That set the impetus for *Perspective*, an ongoing multimedia project that began in 2019, which features contributions from disabled participants worldwide and asks what broad yet disability-specific terms mean to them, with initial questions including:

- What is **access** for you?
- What is **care** for you?
- What is **control** for you?
- What is **weakness** for you?
- What is **strength** for you?
- What is **cure** for you?
- What is **interdependence** for you?
- What is **assumption** for you?

The first iteration was initiated in 2020 for the By the People Festival in Washington, DC, as part of a year-long art and social impact fellowship with Halcyon Arts Lab. This iteration features eighteen disabled participants in DC and worldwide, engaging local constituents while drawing upon the disability community's value of virtual connection often due to mobility impairments. Initial respondents have represented a diverse range of disability identities and fields, including those with physical, neurological, vision, and hearing impairments with veterans, musicologists, activists, former pageant models, and more. The answers have been incredibly varied, including "cure is a fiction," "weakness is my superpower," and come to represent the singular potential and solidarity of the disability perspective, particularly during and after COVID-19 when such concepts of care and interdependence are being critically rethought and re-examined.

The project has since expanded to iterations in Boise, ID and Twin Cities, MN. The iteration in Boise, ID was undertaken through an artist residency at Surel's Place and in collaboration with Open Arms Dance Project, an integrated dance company involving disabled and nondisabled dancers, along with their caretakers. For this iteration, at the beginning of the month-long residency I interviewed several of their disabled dancers with three questions from the original version, specifically those exploring interdependence, care, and strength. Then by the end of the month, I produced musical sections for each question involving the interviewees' voices and my musical underscoring, along with open caption videos to highlight their answers

visually and via text. Finally, this was shared in an event featuring the dances of Open Arms and choreography by their founder, Megan Brandel.

For the iteration in Twin Cities, MN, I interviewed participants over the course of summer 2021 and specifically with new questions/concepts relating to winter. This was in response to this iteration being commissioned by The Great Northern Festival, an annual festival in the Twin Cities that celebrates art and culture related to winter. The questions for this iteration were:

- What is **resilience** for you?
- What is **isolation** for you?
- What is **connection** for you?
- What is **darkness** for you?

This iteration also featured the first in-person installation for the project, specifically with the sound and visual projection installed for a specific space. This was implemented at Second Shift Studio Space in St. Paul, MN.

Following in-person and virtual interviews with each participant, their answers have been featured aurally and visually, including audio playback of the recording of their voices and visual projection in an open captions format. Each corresponding section to the questions involves musical underscoring with my voice, vintage toy organ, and electronic processing of both audio sources, in order to enhance and provide greater depth to their answers and concepts highlighted. This aural combination is a common facet of my practice, including solo and collaborative work and especially as the toy organ is well suited for my physically-different hands and has been a critical vehicle for my artistic output exploring disability as a creative source. Furthermore, over the past three years, I have traveled with artist residencies worldwide with the organ, and these travels are how I came into contact with most of the project interviewees.

In addition to how the music was scored and produced, my curatorial collaborator Sandy Guttman and I took great care to incorporate thoughtful accommodations as a means of providing and considering accessibility as aesthetic. As early as 2019, we discussed the radical potential for exhibiting *Perspective* as a captioned video where the captions were the main

visual focus of the predominantly aural work. In having the captioned interviewee responses comprise the primary image, we took a stance that felt radical, political, and activist. By focusing the visual experience on the open caption itself, we effectively flipped the expectation—the caption is the visual, the primary image rather than an addendum to the work—and in doing so magnifying the interviewees' responses. Interestingly, the preference for something “more visual” than the caption itself was made known when pre-viewers of the work-in-process inquired as to why there weren't images included on the captioned video, an interesting example of the primacy for the visual and a preference for something “other” than accommodations.

Historically, accessibility in American galleries and museums has been absent—though when included, it tends to be treated as an add-on to comply with guidelines for reasonable accommodations per the Americans with Disabilities Act (Guttman, 2018). Typical video and sound installations in a gallery are not captioned or visually described. Touch and tactile interventions are rare occurrences, as galleries and museums are no-and-low touch environments due to the conservation and preservation of the work. When museums do attempt implementing access, it is not uncommon for them to encounter resistance to making video and sound art accessible. A frequent argument against adding any accommodations—typically captioning—changes the original artistic intent and aesthetic virtues. Relatedly, in his foundational text *Disability Aesthetics*, the scholar Tobin Siebers posits that one of the most common arguments from architects against making the built environment more accessible is that accessibility is not aesthetic or beautiful. Access is relatively new in public space: curb cuts weren't made common practice until the 1980s and closed captioning on television wasn't implemented until the 1990s following passage of the ADA. In understanding the “newness” of accommodations within our society—especially within the cultural sector—we must train ourselves not only to demand access but to familiarize ourselves with the aesthetics of accommodations, including the sound of the visual describer speaking into their transmitter, captions appearing on video, CART captioners, and ASL interpreters taking their place on the stage alongside performers.

With this context, as we shaped *Perspective* we considered the possibility of what it would mean to build access into the project from its inception. Given that the work is about the nuanced experiences of disabled people and by a disabled artist, we agreed that access should

be front and center to the work's presentation and experience. Some of the accommodations for our imagined audience included:

- Transcribing the interviews, turning transcriptions into captions.
- Providing image descriptions for the video and installation.
- Incorporating flexible seating formats, inspired by Shannon Finnegan's work.
- Incorporating wearable haptic technology to experience the work through vibrations, in collaboration with WearWorks, an assistive technology company for blind and low-vision users (<https://www.wear.works/>)
- Consulting with blind media artist Andy Slater to compose sound descriptions of the music.
- Creating web-based formats for accessing the work and allowing virtual visitors to select the order in which they experience the compositions
- Virtual access with visual descriptions, interpretation in American Sign Language, CART captioning, and recording programs for relaxed, asynchronous viewing.

Further, in building accommodations into *Perspective* from the beginning across a range of experiential modalities we upheld one of the core tenets of the project: disability as a creative source. In her research and writing on disability art and culture, Dr. Carrie Sandahl points to the untapped and often unacknowledged creativity and ingenuity of disabled people adapting and flexing within ableist social structures. In building access as aesthetic into the project's varying iterations, we acknowledge and honor the value and beauty inherent to the disability experience, and the specific creativity birthed from a disability phenomenology that spreads rhizomatically across communities through clever innovations and disability hacks.

As aforementioned, the work's first iteration was scheduled as a sound and projection installation in Halcyon's *By the People* Festival in June 2020 (canceled due to COVID-19), and has since seen virtual presentations at Americans for the Arts' convention, The Peace Studio's *100 Offerings of Peace*, Bemis Center for Contemporary Arts, The Great Northern, Surel's Place, *Gaudeamus Muziekweek*, which featured an online interactive version involving the

choice of video order for audiences and submission form for viewers to contribute their own answers to the questions.

I am very grateful for these initial presentations, however further research and dialogue are needed to effectively progress the project, specifically in terms of societal context and dialogue. The first showing highlighted several critical concepts to disability culture prior to the onset of COVID-19, and following the impact of the pandemic, it is clear that interdisciplinary concepts and experiences surrounding key concepts of care, control, interdependence, and more are even more essential to interrogate and appreciate. This is specifically in regards to examining new realities brought on by the pandemic, and how many will become disabled by COVID-19. As expressed by writer Amy Gaeta: “Disabled people are experts when it comes to isolation and pandemics. We know how to advocate our legal rights as patients, navigate Medicaid and other private insurance claims, and stock up on supplies for weeks. We know how to live vulnerably, which is to live together.”

This new reality and potential have motivated a larger undertaking with more questions, contributors, and mediums to reach greater diversity, specifically furthering the project’s reach beyond my immediate network including internationally and with refugee populations. Further questions and concepts to be explored include inspiration, vulnerability, comparison, sustainability, wealth, connection, isolation, and productivity.

Additionally, the work focuses on access as not only compliance and accommodation but aesthetic, including aural playback of the interviewees’ voices, open text captions of their answers in video/projection, tactile facets to hear the vibrations of the music, and more to allow multiple sensory inputs and interpretations. The work was initially envisioned as a sound and projection installation however can take the form of installation, video, live performance, digital interaction, and more.

Therefore through *Perspective* I hope to offer a contrasting prospect, one that doesn’t provide singular answers or solutions but rather allows for divergent interpretations and questions to arise in a progressive form. Disability is the largest yet most unacknowledged global minority - affecting 15% of the world’s population according to 2011 WHO/World Bank report, and can be congenital, acquired, permanent, and temporary. Furthermore, nondisabled people rarely gain the opportunity to be up close and intimate with a disability, in physical

proximity and understanding contexts from those with bodies that break from the normative and standard expectation of a human body.

Disability can be considered as the “master trope of human disqualification” (Straus) which “emerges from a society that chooses to accommodate some bodies and exclude others” (Howe et al.). Through highlighting these concepts, questions, and answers, I hope nondisabled people will realize that disability is not only an experience of the hospital but of the pathological and sociological, and rather a singular social offering that can be infinitely learned from and engaged with. With *Perspective* I aim to offer a contrasting prospect and allow divergent interpretations and questions to arise, exploring central concepts made especially relevant with COVID-19, such as care, control, and more.

“Art is not nature, but is nature transformed by entering into new relationships where it evokes a new emotional response.”

— John Dewey, *Art as Experience*

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Care, interdependence, and reasonable accommodation in academia

Shubha Ranganathan¹

What might it mean to think of reasonable accommodation for all? What are the consequences of broadening the scope of reasonable accommodation beyond disability? And why should such efforts even be attempted in higher educational institutions? This paper seeks to reflect on these questions through an examination of the question of reasonable accommodation from a broader context. Here, reasonable accommodation is being considered in line with a variety of other considerations that are impacting higher educational institutions. Thus, for this paper ‘reasonable accommodation’ is not just a ‘disability issue’ that is pertinent to certain categories of persons. Instead, it becomes a framework through which to think through a variety of questions pertaining to inclusion and participation.

Within the context of higher educational institutions, reasonable accommodation is often understood as a bureaucratic exercise of ticking off accommodations that are provided, quite often, on a case-by-case basis. Here, reasonable accommodation largely becomes a check-box activity for institutions. When seen in this administrative sense, reasonable accommodation becomes reduced to a fairly narrow phenomenon. Thus, for instance, HEIs often approach the clause of reasonable accommodation through interventions such as ramps, providing extra time for completing examinations or academic programs, providing technological support for accessing educational materials, affirmative action policies in recruitment, etc. This paper makes a distinction between such bureaucratic responses of institutional care to genuine, individualized responses of care. I refer to the former as *bureaucratic care*, differentiated from the latter, which I term as *contextual care*.

It is useful here to draw a parallel with Saiba Varma’s (2020) explication about mental health care practices in the context of conflict-ridden Kashmir. In this highly militarized context, as she expounds in her striking ethnography, the state engages in what she refers to as *militarized care* practices that reflect the overbearing presence of a paternalistic, controlling, and violent state. The state’s deployment of humanitarian projects in mental health care, such as government interventions for trauma victims, illustrates that militarism and care collapse into each other. Varma distinguishes such militarized care from the *humanitarian care* that is

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engaged in by non-state actors such as NGOs and the *everyday care* that is performed in non-institutional contexts through mundane acts of sharing food and conversations.

What emerges from such an analysis is an understanding of care as rhetoric. This paper extends the idea of care as rhetoric and discourse by looking at examples of bureaucratic and contextual care in HEIs. These examples are drawn from observations based on my own location as a temporarily able-bodied female academic working in a liberal arts department in a central government technological institute in India as well as ongoing research conversations with parents who are caring for an adult child on the autism spectrum, some of whom are themselves academics.

Reasonable accommodation as contextual care

In higher educational institutions, bureaucratic care is often illustrated by the responses of the administration to governmental directives pertaining to affirmative action or reasonable accommodation, whether these pertain to meeting the learning or accessibility requirements of persons or to addressing gender issues or minority representation. For instance, in the Indian context, higher educational institutions are required by law to set up a committee to address issues of gender equity and sexual harassment, typically referred to as the CASH (Committee Against Sexual Harassment) committee. While many HEIs have such committees established, such a step is quite often a tokenistic act that seeks to adhere to the law in letter rather than in spirit. In practice, such committees and cells often fail due to their lack of genuine commitment to gender equality and diversity.

Unlike bureaucratic care, personalized care responses are characterized by efforts to meet the specific requirements of individuals coming from diverse contexts. Such efforts also seek to engage with the intersectional nature of disability-related requirements. To illustrate this, I take two recent examples of Supreme Court directives that illustrate how the RA clause can be broadened in a manner that is inclusive and enabling for a range of persons and not just a narrow category of persons identified as disabled. On February 11, 2021, the Supreme Court of India ruled that it was mandatory to provide a scribe for persons with dysgraphia or Writer's Cramp appearing for the Indian Civil Services Examination.² This ruling overruled the Civil Services Examination Rules of 2018 which mandated that scribes were only permitted for

² <https://ohrh.law.ox.ac.uk/indian-supreme-court-upholds-reasonable-accommodation-for-persons-with-disabilities>

“blind candidates and candidates with Locomotor Disability and Cerebral Palsy where dominant (writing) extremity is affected to the extent of slowing the performance of function (minimum of 40% impairment)”.³ In contrast to this bureaucratic approach to reasonable accommodation and narrow definition of disability, the Supreme Court invoked a broader notion of disability, emphasizing the fact that a range of conditions might impact the writing capability of persons even if they are not explicitly identified as disabilities per se. Further, it referred to the RPwD Act, calling for the state “to develop an appropriate environment guaranteeing equality of opportunity to persons with disabilities. Reasonable accommodation, such as the facility of a scribe, is therefore an enabling instrument for securing substantive equality” (Poddar).

The second incident, occurring in November 2021, involved a petition filed by a student with dysgraphia appearing for the NEET⁴ examination who was denied the additional one hour of compensatory time that is allotted for persons with disabilities. The Supreme Court held that denial of “reasonable accommodation” to a disabled person amounts to discrimination, invoking the RPwD Act.⁵

It is interesting to note that in both of the examples cited above, ultimately, the accommodations that were sought after and more useful were also those which provided care in the form of solutions that were both structural but also individual and specific. It is this contextual quality of reasonable accommodation that is its greatest strength. As explicated in one article, “flexibility in answering individual needs and requirements is essential to reasonable accommodation” and that “reasonable accommodation cannot be construed in a way that denies to each disabled person the customization she seeks.”⁶ The key question that emerges here, is, how do we balance the structural provision of reasonable accommodation with the individualized customization required in specific cases?

To do so requires an understanding of the importance of contextualized care. Here, Annemarie Mol’s (2008) exposition of care as tinkering is relevant. In distinguishing the ‘logic of choice’ from the ‘logic of care’, she elaborates on the value of understanding care as tinkering or ‘doctoring’, where adjustments are constantly made in accordance with situational

³ https://upsc.gov.in/sites/default/files/Notification_CSP_2018_Engl.pdf

⁴ National Eligibility cum Entrance Test (Undergraduate) or NEET (UG), is an all India pre-medical entrance test for students who wish to pursue undergraduate medical, dental, and related courses in government and private institutions in India.

⁵ <https://www.thehindu.com/news/national/denial-of-reasonable-accommodation-to-the-disabled-is-discrimination-says-supreme-court/article37650375.ece>

⁶ <https://www.canefoundation.org/the-right-to-reasonable-accommodations-of-persons-with-disabilities/>

requirements. This is not the kind of care that stems from a professional-centric approach that comes from a position of “unmarked normality” (p. 11). It is an approach towards a care ethics that takes for granted the messy, chaotic, and unpredictable quality of human experience.

Care practices for interdependent living

Mol’s (2008) analysis also sheds light on an approach to care practices that begin from a position of interdependence and relationality rather than a rational choice approach that emphasizes individual responsibility and independence. Here’s Kittay and Feder’s (2002) phenomenal insights into the interdependence of care practices is relevant. Feminist perspectives on dependency have highlighted the fact that care and caregiving are embedded in interdependent relations. Disability has the powerful potential to challenge conventional notions of independence and capacity that have dominated western philosophy and rationalism (Kittay, 2019).

At this point, I would like to draw from ongoing research with parents of adults on the autism spectrum, based on online interviews conducted about experiences of care and kinship in Covid times. All of these parents were temporarily able-bodied persons whose adult children had varying support requirements, although most of them were towards the moderate or severe end of the spectrum. Many of these parents were in their fifties and sixties, with children in their twenties or thirties.⁷ Many of them had been active in the autism movement and were running organizations providing support and services for autism. They were also central figures in autism-related advocacy and legislation (Dhanda, 2018). This particular demographic combination of middle-aged parents (mostly mothers) of adult children raises particular questions about care relations, as I discuss below. Essentially, what emerged was that care was very much of a dyadic, interdependent process, in which both the autistic adults as well as parents had support requirements of different kinds. Thus, as one parent in her late 60s, Daisy, who was a pioneer in the autism movement in the country, founding an organization in 1991, spoke about the need to think about reasonable accommodation in terms of support requirements for all, rather than in terms of reasonable accommodation only for the disabled. In talking about a spectrum of support needs, she emphasized, “we all have support needs. There are things for which I need support too.” Daisy’s statement dispelled the binary of

⁷ For reasons of confidentiality, I do not use real names of people, institutions, and organizations. I use pseudonyms for interlocutors.

disabled and non-disabled, highlighting the need to think about accommodations for all persons with support needs, disabled or not.

Another aspect that many parents emphasized was their family's journey in their search for independent living options for the future. As aging loomed in the horizon, parents wondered about the care needs of both aging parents and children with IDD. For many of the parents, who were in their fifties and sixties, the concern was both how would their children be taken care of after their parents' time, as well as, who would care for the parents when they aged. Thus, Kiran described how she and her family had been exploring housing communities for their future that would be suitable for their different requirements. For Kiran's family, it was a senior citizen housing community that appeared to fit the bill, as she described:

...The only reason we resisted these senior citizen's places is because we go there as seniors, but he's going to be there in his prime with nobody to interact with who's like him. But now we saw that there was one within a bigger township with regular towers and bungalow colonies and a school and a mall, and, you know, all of that, and we thought, 'ok, this is something we can try out. So for the last five years we have been coming here and now we have a flat here with two bedrooms in it and Moksh (son) has been using one of the bedrooms and we are using the other bedroom and the equipment here is also basic, like the washing machine is a very simple one so Moksh can use it.

Importantly, Kiran imagined the township and community as one that could potentially allow for exchanges between people with varying support needs. She went on:

So we are hoping that in time he has enough connections within the society and with the support that is possible in this place, that we could move out and we maybe give our space to somebody else with support needs; it could be a senior on a wheelchair who's younger than us, or it could be another person with uh, not intellectual disabilities, but some other kind of requirement, maybe a person with cerebral palsy or something. And then maybe the two of them with the support that is required, might be able to stay on here... It's all an experiment; it may not work, but I thought while we are still young and able, let's give it a try, if it doesn't work, of course, there are residential homes.

For many other parents, residential options such as group living facilities or group homes were the preference, but Kiran's narrative suggested a preference for a housing option that was more integrated in the community. As she elaborated:

We just preferred this rather than opting for a residential place, based on the same thought process of looking at society as a diversity. Why should there be an exclusion, why should there

be a group of people staying separately? The group staying in this residential is more speckled and then it's of further benefit to everyone... I mean Moksh teaches as much as he learns and he gives as much as he gets from just being... So, from that thought process, we thought, let's try this. I mean we are totally prepared for it not panning out the way we expect.

While Daisy and Kiran's narratives are not articulated within the context of higher educational institutions, they do have important implications for how care needs and reasonable accommodations might be better approached from an ethic of interdependence and mutuality than independence.

Reasonable accommodation for all in academic spaces

Finally, I want to draw some reflections from ongoing conversations with another parent whom I call Vaishali, who is also an academic who has been working since 20 years in a central government educational institution. This parent is in her fifties with two sons in their twenties - one neurotypical and one on the autism spectrum. At the time she had started her career, her son had just been diagnosed with autism. Vaishali highlighted the considerable amount of support received from the institution, to be able to work in the city of her choice, as well as support from department colleagues in negotiating work responsibilities. What helped her case considerably was the fact that the then Director of her institution was familiar with autism, due to a relative of his being recently diagnosed. His sensitivity and openness to her situation was, she felt, out of the norm. While her own experiences of support from the institution was predominantly positive, Vaishali also highlighted the ad-hoc manner in which accommodations are often provided. As she put it, "a lot of things happen in an informal way. That is good in a way, but then it also becomes just an obligation. There is an ad-hocism about it." In the absence of a structure in place for reasonable accommodations, individuals end up using various devices to negotiate their spaces in their own way. Vaishali's point highlights how reasonable accommodations need to be seen in both structural and contextual ways. On the one hand, the support that she received was based on individual-level transactions; on the other hand, it was these very personalized networks that actually benefitted her.

Further, she also elaborated how reasonable accommodation is relevant not just in the case of disability but also for women, those with mental health conditions, those involved in extensive caregiving. To illustrate this point, she gave two examples from higher education. The first pertains to government regulations around Child Care Leave in public institutions. Child Care Leave was first introduced in the 6th pay commission and subsequently underwent

several modifications. As per the 7th pay commission “Child Care Leave or CCL is granted to women employees for a maximum period of two years (730 days) during their entire service for taking care of their minor children (up to eighteen years of age)”⁸. There have been several demands to broaden the scope of this provision (to single fathers, or doing away with the ‘minor’ clause). Thus, as Vaishali recalled, “I couldn’t ever avail of CCL because by the time it came, my children were already adults.”⁹

The second example that Vaishali elaborated on pertained to rules and directives about career advancement as laid out in the University Grants Commission. With new rules for Career Advancement Scheme (CAS), educational institutions and departments were compelled to measure academic output in very specific ways. In an attempt to adopt international standards in education, there was increasing emphasis on measuring and quantifying research output, even though the support for research was typically dismal in many universities and institutions. Pressures on institutions to compete in rankings at national and international levels meant that academics felt the brunt of having to prove their academic output in narrowly defined terms such as the number of publications of a specific nature and number. Such stipulations, by design, often tend to discriminate against people having significant care responsibilities including women academics, young mothers, academics caring for aging parents or disabled family members, and a whole host of other academics experiencing structural barriers. What is particularly noteworthy is the absolute lack of legislative recognition of the tremendous challenges that women academics in India have faced over the last two years of the pandemic. While the fact that the pandemic has been a stark example of how reasonable accommodations have suddenly been included so easily for PwDs even though they desired for a long time has been highlighted by some (e.g. Kurian, 2020) Vaishali’s concern was about how to expand on and draw on the concept of reasonable accommodation for a variety of other contexts beyond disability.

Ultimately, the examples and conversations quoted in this paper all point to the need for thinking about reasonable accommodation in a broader context, in ways that can move beyond the disabled/non-disabled binary, and in tune with an ethics of care that takes for granted the fundamental interconnectedness of lives.

⁸ <https://7thpaycommissionnews.in/7th-cpc-report-on-child-care-leave-ccl/>

⁹ Child Care Leave was first introduced in the 6th Pay Commission in 2014.

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