

EVALUATING PRENATAL CARE FOR PATIENTS WITH PHYSICAL DISABILITIES

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By

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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PRENATAL CARE FOR PATIENTS WITH PHYSICAL DISABILITIES: WHAT IS WRONG WITH THE MEDICAL EXAMINATION TABLE?

A 2013 study found that patients with disabilities are more likely to experience delayed and unmet healthcare needs (40% and 23%, respectively) than non-disabled patients (24% and 10%, respectively) (Henning-Smith et al., 2013, Results section). One specific example of technology that may contribute to these unmet healthcare needs is the medical examination table, which is the center of doctor-patient interaction, and thus a medical device that most patients will have interacted with from a very young age. While many patients may take access to this table for granted, the medical examination table provides a significant barrier to access for many patients who may have mobility-limitations (Story et al., 2004). Standing at 32 inches tall, the medical examination makes patient transfer from a wheelchair at 19 inches high difficult, leaving patients to be examined in their wheelchairs and receive a less thorough screening ("Accessible medical examination tables and chairs", 2017, "Access to medical care", 2010). This, in turn, has caused patients with physical disabilities to receive poorer-quality preventative diagnostic screenings than their able-bodied counterparts, which may negatively impact their health (Maragh-Bass et al., 2018). One field of medicine where the medical examination table is especially important is prenatal care, for which the medical examination table is used to perform prenatal ultrasounds and additional prenatal screenings and diagnostic tests (Smeltzer et al., 2016). However, the medical examination table is merely one example of the exclusion of women with physical disabilities in prenatal care. The prevalent bias that women with physical disabilities are unfit to be mothers has contributed to the exclusion of this demographic from many aspects of prenatal care, ranging from medical devices to clinical knowledge (Iezzoni et al., 2015a, Mitra et al., 2017).

Through redesigning the medical examination table, which will be conducted throughout the 2021-2022 school year under the guidance of advisor Dr. Masahiro Morikawa, MD., a doctor at UVA Family Health, and alongside team members Clara Bosworth, Sarah Cobb, and Lauren Louw, it may be possible to increase the accessibility of this device to various patient demographics and subsequently improve doctor-patient interaction. The technical project, tightly coupled with an STS issue analysis paper that will examine the state of prenatal care and identify areas for reform through an adaption of Law and Callon's 1988 Actor Network Theory, aims to improve health outcomes for patients with mobility limitations.

BIASES AGAINST MOTHERS WITH PHYSICAL DISABILITIES

DISABILITY-BASED BIASES

A key bias that exists in the non-disabled population is the belief that people with disabilities live a lower quality of life, when in reality, people with disabilities often feel equally fulfilled in their lives as those who do not have disabilities (Wolbring, 2003, pp. 144). In his essay "Confined to your legs", disability scholar Gregor Wolbring addresses the medical model of disability, which views disability as a medical problem that is inherent to the "afflicted" individual and results in "a deviation from societal norms and a putative low quality of life for the person and his or her relatives" (Wolbring, 2003, pp. 142). The medical model of disability refuses to accept and accommodate disability, and has influenced modern medicine to increasingly attempt to eliminate disability using science and technology, despite most people with physical disabilities being satisfied with their quality of life.

In contrast to this model, Wolbring discusses the social model of disability, compared graphically to the medical model of disability in Figure 1 below, which "sees disability as a socially defined problem that can be addressed in ways that allow full integration of individuals

into society” (Wolbring, 2003, pp.146). The social model of disability calls for societal action or reform to better accommodate the diverse needs of individuals with disabilities, which may or may not include the use of technology to better aid individuals with disabilities so that they may have equitable access to the same rights and privileges as their non-disabled counterparts (Wolbring, 2003). Wolbring likens the eventual acceptance of the social model of disability to other social movements that have occurred throughout the 20th century, such as a previously male-dominated society making room for women (Wolbring, 2003). However, despite the potential of the social model of disability, Americans who live with a mobility-limitations are still a minority, comprising roughly 13.7 % of the population, according to the Centers for Disease Control and Prevention (CDC) as of 2020. This minority status likely contributes to the dominance of the medical model of disability, which is revered by non-disabled individuals according to Wolbring, despite many disabled Americans simply wanting to live in a society that accommodates their needs as opposed to one that seeks to change who they are.

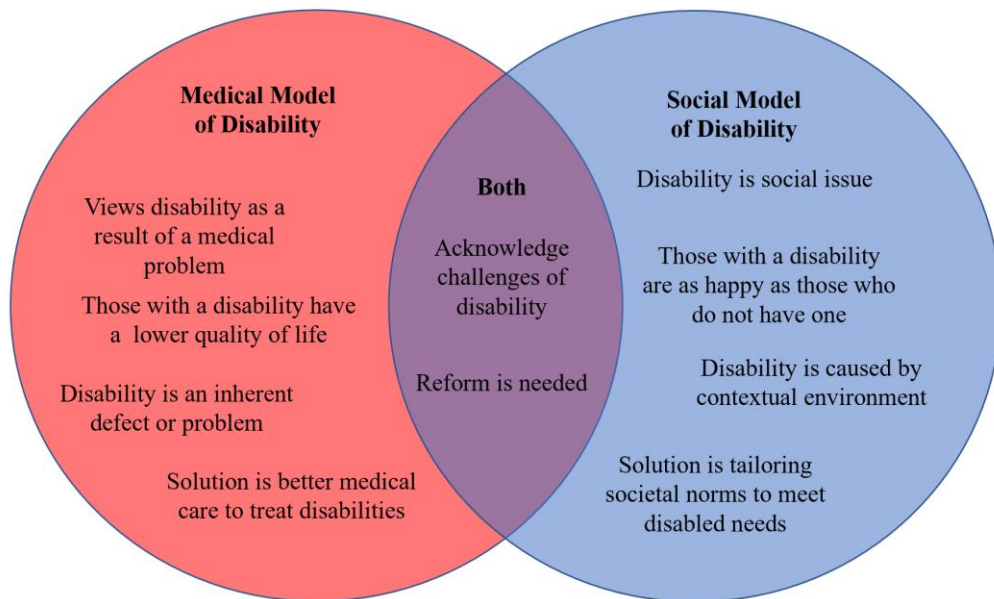


Figure 1: Medical versus social model of disability. This figure compares and contrasts the medical and social models of disability. (Adapted by Harvey (2022) from Wolbring, 2003).

EXPLORING THE INTERSECTION OF DISABILITY AND GENDER ROLES

In her article “Less work for mother?”, Ruth Schwartz Cowan, American scholar in the history of technology, explores how the industrial revolution in the United States influenced gender roles in the average American two-parent household, specifically how technology shifted the role of mothers in parenting (Penn Arts & Sciences, n.d., Cowan, 1987). Prior to the introduction of many commonplace technologies in today’s society, which took place from 1920 to 1960 in what Cowan refers to as the “industrial revolution of the home”, the average American housewife logged 50-60 hours of unpaid work in her home (Cowan, 1987, pp. 58). While one might have expected this number of hours to decrease with this technological revolution, which yielded technology such as the vacuum cleaner, laundry machine, and family automobile, housewives were logging the same number of hours in the 1960s as they were in the 1920s (Cowan, 1987). Technologies that replaced the previous “drudgery” of household work allowed “a woman to put in a double day without destroying her health”, thus freeing women to enter the workforce by the second half of the 20th century while still maintaining their status as primary caregiver for their family (Cowan, 1987, pp. 62).

Not only did household technology improve, but at-home medicine improved, too. Long hours spent nursing sick children back to health were eliminated by improved prescription and over-the-counter drugs that mothers could administer to children in a matter of seconds (Cowan, 1987). Thus, by the 1960s, the typical image of a mother had evolved to become a woman who was able to perform all household tasks such as cooking, cleaning, and chauffeuring her kids and husband, nursing her children if they should fall ill, and financially support her family by going to work. This idealized figure of motherhood, combined with the medical model of disability that views disability as an inherent medical hindrance that results in a lower quality of life,

makes the concept of women with physical disabilities being capable and caring mothers unthinkable, when accepted rigidly.

Thus, it should come as no surprise that women with physical disabilities have faced extreme bias regarding their decision to become mothers. Renowned disability and healthcare researcher and Professor of Medicine at Harvard Medical School, Lisa Iezzoni, found in her 2015 study entitled “‘How did that happen?’ Public responses to women with mobility disability during pregnancy” that pregnant women with physical disabilities experienced being questioned and doubted for their abilities to become pregnant and care for their children (Dana-Farber/ Harvard Cancer Center, n.d., Iezzoni et al., 2015a). Out of a study of 22 women with mobility limitations, roughly two-thirds of them reported different public responses to the coexistence of their disability and their pregnancy, compared to when they were not pregnant (Iezzoni et al., 2015a). Iezzoni et al. characterized public reactions into 6 separate categories: curious, intrusively curious, hostile, questioning competence, oblivious, and positive. Responses that were hostile suggested that expectant women with disabilities were bringing a child into society that would eventually become a burden, with one interviewee recalling “getting ‘dirty looks,’ which said to her ‘how horrible I am to bring a baby into this world when I’m not even fit to be a mother – just very hateful things like that’” (Iezzoni et al., 2015a, Hostile section, para. 1).

Iezzoni et al. also depicted several interactions that indicate disbelief in the general public regarding the ability of women with physical disabilities to become pregnant. Many of the women surveyed reported being asked how they became pregnant, assuming that women with physical disabilities did not have the adequate reproductive system or sex life to carry a child to term (Iezzoni et al., 2015a, Intrusively curious section). Several women in Iezzoni’s study also reported doubts about whether non-disabled women received similar questions regarding their

reproductive capabilities during their pregnancies, underscoring the concept that women with physical disabilities face undue skepticism surrounding their pregnancies and subsequent motherhood (2015a). Thus, it should come as no surprise that these biases cultivate a culture in which motherhood in women with physical disabilities is not thought of as possible, valid, or worthy of care.

RACIAL AND ETHNIC DISPARITIES

Despite the main focus of this sociotechnical analysis being to evaluate prenatal care for women with physical disabilities regardless of race, special notice must be given to the inequities that exist in prenatal care on a racial and ethnic basis to provide a more comprehensive view of this issue. Research has indicated that black and American Indian/Alaska Native mothers have a higher mortality rate from pregnancy-related complications than white women, despite the fact that “most pregnancy-related deaths are considered preventable” (Artiga et al., 2020, para. 5). It is also important to note that in 2020, the CDC reported that American Indian/ Alaska Native and black populations have the highest prevalence of disability, with 30% and 25% of each population, respectively, identifying as disabled. While the analysis in this paper is meant to apply to physically disabled mothers regardless of race and ethnicity, the higher rates of disability and mortality in prenatal care for these communities may indicate a greater need for reform than in other racial and ethnic groups, meaning that reform should be focused on serving these communities in ways that are equitable to others.

EXAMINING BARRIERS TO ACCESS OF PRENATAL CARE FOR WOMEN WITH PHYSICAL DISABILITIES

MEDICAL DEVICES

In a 2017 study, Monika Mitra, co-leader of the National Research Center for Parents with Disabilities at Brandeis University and co-editor-in-chief of the Disability and Health

Journal, conducted phone interviews with healthcare practitioners who had expertise in obstetrics/gynecology and previous experience treating WWPD in a maternity care setting (Brandeis Faculty Guide, n.d.). In this study, Mitra et al. identified a lack of accessible medical equipment to cater towards the diverse needs of patients with physical disabilities as a barrier to access for prenatal care, with two medical devices that the interviewed practitioners discussed being medical examination tables and scales for weighing pregnant patients, which are commonly used in prenatal care (Mitra et al., 2017). For women with physical disabilities, Mitra et al. reported that medical examination tables were often inaccessible unless they had a height-adjustable component for wheelchair-using patients; without transferring patients onto the table, the performance of crucial ultrasounds and vaginal examinations for this demographic is hindered (Mitra et al., 2017). Ultrasounds during pregnancy are typically conducted on a medical examination table to check on fetal health, with information such as the size, bodily growth and development, heartbeat, and potential defects of the fetus being collected; failure to obtain this information can lead to medical complications later in pregnancy (Johns Hopkins Medicine, n.d.). In another study conducted by Lisa Iezzoni, women with physical disabilities who had received prenatal care even reported being dropped in the transfer process from a low wheelchair to a tall medical examination table despite the help of doctors and other assistants, which could be detrimental to a developing fetus (Iezzoni et al., 2015b)

In addition to the medical examination table, both Mitra et al. and Iezzoni et al. identified scales with which to weigh pregnant women as inaccessible for many women with physical disabilities. Some interviewees in Iezzoni's study report not being weighed during pregnancy for a lack of a scale that could accommodate their disability, for example if they used mobility aids for support, and thus reported not knowing their weight throughout their pregnancies (Iezzoni et

al., 2015b). Thus, at a clinical level, there exists a need for medical devices and equipment to be more accessible for women with physical disabilities to protect the health of expecting mothers and developing fetuses. Merely being able to enter the door of the doctor's office with a handicap-accessible ramp does not suffice.

LACK OF PHYSICIAN AND MEDICAL KNOWLEDGE

While a lack of accessible medical examination equipment is enough to cause a significant barrier to care for women with physical disabilities, these barriers penetrate much deeper into healthcare than just medical devices. In addition to an absence of accessible medical examination equipment, a lack of physician and medical knowledge surrounding the prenatal care needs of women with physical disabilities has been indicated in literature (Mitra et al., 2017, Smeltzer et al., 2016). Mitra et al.'s study, which was conducted through a series of interviews with healthcare practitioners who had experience delivering perinatal care to women with physical disabilities, found both "(1) Lack of maternity practice guides and (2) Lack of disability-specific clinical information and data on the interaction of disability and pregnancy" (Mitra et al., 2017, Barriers Related to Lack of Evidence section, para. 1). Practitioners reported a desire for prenatal or perinatal care guidelines for women with physical disabilities; however, few of the interviewed practitioners knew of such an existing set of guidelines (Mitra et al., 2017). The participants in this study also noted that there is a lack of data available surrounding pregnancy in women with physical disabilities. While this is likely due to the complexity of each unique disability and patient, it has led to some practitioners reporting that they felt like they had to extrapolate information from other patient demographics and perform on-the-job learning while treating patients with physical disabilities (Mitra et al., 2017).

In another study, Suzanne Smeltzer, director of the College of Nursing's Health Promotion for Women with Disabilities Project at Villanova University, and Monika Mitra interviewed women with physical disabilities to discover their recommendations for perinatal care (M. Louise Fitzpatrick College of Nursing, n.d.). Through this series of interviews, Smeltzer et al. corroborated the work of Mitra et al.'s 2017 study above, indicating that both doctors and patients are aware of the absence of knowledge that exists specific to the needs of women with physical disabilities during pregnancy (Smeltzer et al., 2016). However, Smeltzer et al. also uncovered that many practitioners were enthusiastic about learning about their patient's unique disability and finding better ways to cater their care towards each patient's needs (Smeltzer et al., 2016). This willingness to learn indicates a need in medical school curriculums and standard medical practice that is currently unmet, and efforts to seek more medical knowledge about the diverse needs of women with physical disabilities will help this demographic obtain better prenatal care going forward.

However, despite the fact that many patients perceived their practitioners as ready to learn, other patients reported that their practitioners were dismissive of their own learned experiences and knowledge surrounding their disability (Smeltzer et al., 2016). Going forward, the participants in Smeltzer's study asked that clinicians listen to and respect the knowledge of women with physical disabilities, and treat them with the same respect that they treat other, non-disabled patients who are receiving prenatal care (Smeltzer et al., 2016). While it may be difficult to gather extensive and all-encompassing data on the unique pregnancy experiences of all women with physical disabilities, treatment of patients with physical disabilities offers a unique opportunity for doctors to gain knowledge with firsthand experience going forward, and

in turn spread awareness in the medical community about how best to meet the complex needs of this patient demographic.

ETHICAL AND STS FRAMEWORK ANALYSIS

ETHICAL FRAMEWORKS

One possible reason for the disparities that exist between the standard of prenatal care for non-disabled women and women with physical disabilities may be the use of ineffective ethical theories. While all ethical theories are in some way a framework that guides others towards making ethical choices, each theory may define what is ethical in drastically different ways. In the case of prenatal care, two contrasting ethical theories that may apply are utilitarianism and rights/duties ethics. Utilitarianism is a popular guiding principle for many engineers, as the goal is to do the greatest amount of good for the most people (Martin & Schinzinger, 2009). However, rights and duties ethics concern each individual's fundamental rights, and the duties of others to respect and protect those rights (Martin & Schinzinger, 2009). From a utilitarian perspective, a doctor or engineer who designed medical devices or a medical school curriculum would be concerned with helping the greatest amount of people; for example, the 86.3% of the U.S. population who does not identify as physically disabled, according to the CDC (2020). Viewing this issue instead from the perspective of rights and duties ethics would encourage the notion that despite the minority status of disabled Americans, everyone has the right to life, liberty, and property, and conversely, a duty to protect those rights for other people. Thus, viewing the protection of these rights for Americans with disabilities as a duty, rather than an afterthought, may help this demographic be better served in healthcare going forward.

ACTOR NETWORK THEORY ANALYSIS

Another framework that can be used to analyze the complexity of the field of prenatal care is Law and Callon's 1988 Actor Network Theory (ANT). By using an ANT analysis, pictured in Figure 2 below, to explore the landscape of prenatal care, gaps and vulnerabilities in the network can be exposed to indicate potential areas for reform. Figure 2 illustrates the Actor Network Theory analysis for the current state of medicine, disability, and prenatal care, with the black lines indicating a relationship between actors in this network.

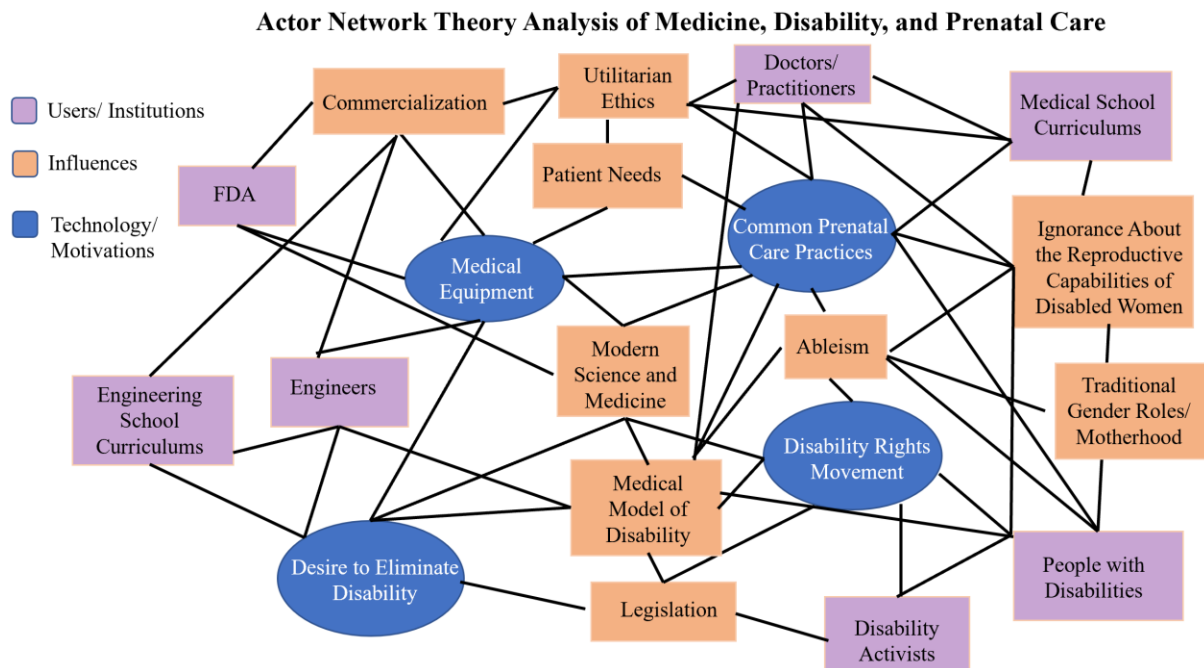


Figure 2: Actor Network Theory analysis of medicine, disability, and prenatal care. This figure provides a visual for the complicated network of prenatal care, comprising the users, institutions, technologies, motivations, and influences that exist in this network. (Adapted by Harvey (2021) from Law and Callon, 1988)

The diagram illustrates how common prenatal care practices, such as the knowledge and treatments that doctors prescribe to most of their pregnant patients, are influenced by a variety of factors, such as medical school curriculums, doctors and practitioners, utilitarian ethics, patient needs, modern science and medicine, the medical model of disability, ableism, and ignorance

surrounding the reproductive rights and capabilities of women with disabilities. Additionally, the diagram highlights how medical equipment interacts with multiple actors, such as the FDA, commercialization, patient needs, utilitarian ethics, engineers, the desire to eliminate disability, and modern science and medicine. It is important to note that medical equipment and common prenatal care practices influence each other; for example, the common practice of weighing expecting mothers is performed using a scale, and both this action and the need for this medical device depend on each other.

Additionally, the desire to eliminate disability and the disability rights movement are depicted in the diagram above. While these two motivations share many similar influences, they are at odds with one another, because the disability rights movement is rooted more in the social model of disability than in the medical model of disability, which the desire to eliminate disability stems from. An important influence that these two motivations share is legislation, which will be examined further in the conclusion. Thus, by highlighting these relationships and treating each actor as equally capable of affecting other actors in the network, regardless of how small or implicit any actor may seem, gaps and avenues for change can be identified in the current network.

CALL TO ACTION: FUTURE WORK IN IMPROVING THE STANDARD OF PRENATAL CARE FOR PATIENTS WITH PHYSICAL DISABILITIES

From the above ANT analysis, legislation, medical school curriculums, and engineering school curriculums are some of the actors that can be modified to better serve women with physical disabilities seeking prenatal care. While 1990's Americans with Disabilities Act, which mandates accessibility of privately-owned and government-operated healthcare facilities for patients with disabilities, made great strides in improving healthcare for disabled Americans, this demographic is still largely underserved, indicating a need for stronger legislation ("An overview

of the Americans with disabilities act”, 2017). In his article “What if disability rights were for everyone?”, disability rights scholar Ari Ne’eman acknowledges that many of the accommodations being granted to protect the general public from Covid-19 have been needed by disabled Americans for years; however, these accommodations were not granted due to the minority status of Americans who actively identify as disabled (Ne’eman, 2021). Ne’eman posits that the pandemic may positively influence disability rights by broadening the definition of disability and allowing more people to identify as disabled, and in turn promote more Americans to support and expand disability rights advocacy and legislation. Thus, it is possible that in the near future, a more encompassing and effective disability rights legislation will be introduced that requires accessible medical equipment at all clinical sites.

In the case of medical school curriculums, change can be enacted at an early stage in the careers of the highly trained professionals who provide care and medical devices for patients. Medical school curriculums could be adapted to highlight some of the unique prenatal care needs of women with physical disabilities, as demonstrated by the research of Smeltzer et al., Mitra et al., and Iezzoni et al. (2016, 2017, 2015b). The work done by these researchers highlights that both practitioners and patients are aware of the need for a reformed curriculum that better grasps the diverse needs of this patient demographic, and open communication and listening between women with physical disabilities and their practitioners may be one way to accomplish the development of clinical data that can be used to serve women with physical disabilities who receive prenatal care in the future.

Engineers also share some blame for the inaccessibility of standard prenatal care medical devices. A qualitative study spanning three years in a university engineering program explored the understanding, or lack thereof, that engineering students have regarding the social relevance

and ethical impact of their coursework (Lim et al., 2021). The study found that engineering students seemed more concerned with microethics than macroethics, which the authors define as concern for an engineer's peers and clients versus concern for greater societal implications (Lim et al., 2021, p. 7). Interestingly, the study also found that many students showed apathy towards ethics as a whole, believing that they were at school to learn technical skills, not right from wrong (Lim et al., 2021, p. 16). The findings of this study highlight the need for engineering programs to underscore the societal and ethical implications of the technical work that engineers perform on a daily basis. Perhaps if engineers are educationally trained to better identify the various demographics their inventions may be used by, accessible medical equipment may become commonplace in doctor's offices.

THE PATH FORWARD

Regardless of what the path forward in improving the standard of prenatal care for women with physical disabilities looks like, the research, ethical analysis, and Actor Network Theory analysis put forth in this research paper may serve as a framework with which to view this entangled network. An STS analysis such as this allows for the recognition of the complexity of the current state of prenatal care, which is fully comprised of its technical, ethical, and social influences, and must be viewed as the sum of its parts in order to be fully understood. However, the beauty of this complexity is that it allows for reform in any one aspect of this network to ripple through the other actors, eventually causing noticeable and meaningful change for disabled and non-disabled prenatal care patients alike. There is hope that with intentional legislative and curriculum reform, the biases that hinder women with physical disabilities can be destroyed, and a future with improved prenatal care for all can be realized.

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