

# DIAGNOSING DISCRIMINATION: HOW LEGAL GAPS AND BUSINESS PRACTICES FAIL WOMEN WITH DISABILITIES IN HEALTHCARE

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## ABSTRACT

*Women with disabilities are legally vulnerable and are not believed by healthcare providers. They face the additional challenge of proving they are disabled, often while overcoming existing historical, medical, and legal frameworks that view them as defective. The explicit and implicit bias of healthcare professionals creates an othering effect, leading to diagnostic errors. This cycle, in turn, perpetuates ongoing health disparities plaguing women with disabilities in healthcare. In general, women are more readily dismissed by healthcare professionals than men, and experiencing a disability, especially when it is non-apparent, adds another layer of challenges. Unfortunately, these women cannot turn to our legal system for recourse. Current disability antidiscrimination law is inadequate and fails to provide sufficient protections, leaving these women vulnerable to the persistent biases riddling the U.S. healthcare system. Further, the existing legal framework does not account for non-apparent disabilities –those who are not able enough and not disabled enough. Alongside pitfalls in our legal and medical systems, women with disabilities must advocate for themselves to receive adequate treatment. Their experiences and challenges are compounded as the US healthcare system frequently overlooks and devalues their humanity. This Article examines key legal and theoretical frameworks alongside the intersection of gender and disabilities and exposure to diagnostic error. This paper bridges this intersection by examining women with disabilities, with a focus on those with non-apparent disabilities, their exposure to diagnostic error, and their overall treatment within the healthcare system.*

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## INTRODUCTION

*“First, do no harm” – Hippocratic Oath*

Healthcare systems are built on the foundation of “first do no harm.”<sup>1</sup> Sadly, for American women with disabilities, the harm begins from the moment they interact with the healthcare system. To start, it is important to define and distinguish between illness and disability. Unfortunately, society erroneously conflates the two, but illness is separate from disability. The Merriam-Webster dictionary has defined illness as “an unhealthy condition of body or mind.”<sup>2</sup> As such, illness is perceived as something that needs to be fixed or treated. A disability relates to how an individual is socially treated. As society fails to distinguish between illness and disability, people with disabilities (“PWD”) are perceived as defective

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1. See INST. OF MED., TO ERR IS HUMAN: BUILDING A SAFER FUTURE 3 (Linda T. Kohn, Janet M. Corrigan & Molla S. Donaldson eds., 2000); see also Klea D. Bertakis & Rahman Azari, *Patient-Centered Care Is Associated with Decreased Health Care Utilization*, 24 J. AM. BD. FAMILY MED. 229, 229 (2011).

2. *Illness*, MERRIAM-WEBSTER (Sep. 5, 2025), <https://perma.cc/9N4Z-VK69>.

and in need of treatment. This paper argues that disability is socially constructed, rather than an individual problem. Instead, illness needs to remain within the purview of medicine, and disability needs to be addressed socially and legally.

The World Health Organization has defined disability as having three dimensions.<sup>3</sup> The first dimension is impairment. This refers to the diminishment or loss in a person's body or mental functioning.<sup>4</sup> Some examples of such impairments include "losing a limb, loss of vision, or memory loss."<sup>5</sup> There may also be impairments not readily apparent to the untrained eye.<sup>6</sup> The second dimension is activity limitation,<sup>7</sup> which may include difficulty seeing, hearing, walking, or problem-solving.<sup>8</sup> Third, is the restriction of participating in normal daily activities—such as walking, engaging in social and recreational activities, and obtaining health care and preventive services.<sup>9</sup> The Centers for Disease Control (the "CDC") defines disability as "any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)."<sup>10</sup>

Disability has also been defined in various contexts. Legally, disability is defined as "a physical or mental impairment that substantially limits one or more major life activities of such individual."<sup>11</sup> As evidenced by this definition, the law holds people with disabilities to an able-bodied<sup>12</sup> standard. Under this standard patients with disabilities are othered. More on the legal framework of disability in section IV.

#### *Disability – Distinguishing this Population*

*Regardless of the particular diagnosis or labels, every individual's experience with disability is unique.*<sup>13</sup>

Over 20% of women in the U.S. have some type of disability.<sup>14</sup> More than half of Americans 65 and older have a disability—and of this population, two-thirds

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3. *Disability and Health Overview*, CDC (Apr. 2, 2025), [<https://perma.cc/AH3R-9RM5>].

4. *Id.*

5. *Id.*

6. See Susan Lingsom, *Invisible Impairments: Dilemmas of Concealment and Disclosure*, 10 SCAN J. DIS. RSCH. 2, 2 (2008). See also Mike Oliver, *Defining Impairment and Disability: Issues at Stake, in EXPLORING THE DIVIDE: ILLNESS AND DISABILITY* 44 (Colin Barnes & Geof Mercer eds., 1996). See generally MICHAEL OLIVER, *THE POLITICS OF DISABLEMENT* (1990).

7. See CDC, *supra* note 4.

8. *Id.*

9. *Id.*

10. *Id.*

11. 42 U.S.C. § 12102(1)(A) (2024).

12. See Labib Rahman, *Disability Language Guide*, STANFORD DISABILITY INITIATIVE (July 2019), <https://perma.cc/57SW-P7GF>. (While this source advocates against the use of able-bodied, other literature suggests it is one of the inclusive ways to term able-bodied).

13. See, e.g., Suzanne C. Smeltzer, Nancy C. Sharts-Hopko, Barbara B. Ott, Vanessa Zimmerman & Janice Duffin, *Perspectives of Women with Disabilities on Reaching Those Who Are Hard to Reach*, 39 J. NEUROSCI NURS. 163 (2007).

14. Suzanne C. Smeltzer, Nancy C. Sharts-Hopko, Barbara B. Ott, Vanessa Zimmerman & Janice Duffin, *Perspectives of Women with Disabilities on Reaching Those Who Are Hard to Reach*, 39 J. NEUROSCI NURS. 163 (2007).

are women.<sup>15</sup> Individuals who have one type of disability frequently have others.<sup>16</sup> People with disabilities, or PWD, is sometimes used to refer to a single population. This can be misleading as individuals with disabilities are a diverse group of people who have a wide range of needs.<sup>17</sup> Two people may have the same disability but be affected differently.<sup>18</sup>

The recognition of health disparities and differences in care for PWD is significant, especially when it comes to women. It is widely known that women with disabilities receive health care that is subpar, less aggressive, and inferior to the care received by women without disabilities.<sup>19</sup> The U.S. Department of Health and Human Services (HHS) has sought to address this blatant gap. In *Healthy People 2010*, HHS stated a goal of promoting “the health of people with disabilities, preventing secondary conditions, and eliminating disparities between people with and without disabilities in the U.S. population.”<sup>20</sup> To address this goal, HHS called for two things.<sup>21</sup> First, the reduction or elimination of disparities in healthcare for women and PWD.<sup>22</sup> And second, providing quality health care to women and PWD. HHS listed both goals as national priorities.<sup>23</sup> HHS has continued to focus on the health of PWD in both *Healthy People 2020* and *Healthy People 2030*. Unfortunately, repeated efforts introducing goals to improve the health of women and PWD indicate a lack of follow through in addressing disparities faced by these populations.

This Article is designed to explore the challenges women with disabilities face within healthcare and recognize the legal pitfalls and failures to protect this population. To address these points, this article engages with anti-discrimination disability law and historical frameworks. Section I examines the key aspects within the history of medicine, including: medicine being built on the white male body<sup>24</sup> and the concept of female hysteria. This section also describes experiences of women with disabilities and the ways they are

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15. *Id.*; see also U.S. CENSUS BUREAU, P70-73, AMERICANS WITH DISABILITIES: 1997 (2001).

16. KRISTINE HAMANN & SHANNON SCULLY, VICTIMS, WITNESSES, AND DEFENDANTS WITH MENTAL ILLNESS OR INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: A GUIDE FOR PROSECUTORS (2020).

17. See CDC, *supra* note 4.

18. *Id.*

19. See Smeltzer, Sharts-Hopko, Ott, Zimmerman & Duffin, *supra* note 14; Joann M. Theirry, *Observations from the CDC: Increasing Breast Cancer and Cervical Cancer Screening Among Women with Disabilities*, 9 J. WOMEN'S HEALTH & GENDER BASED MED. 9 (2000).

20. CDC & NAT'L INST. ON DISABILITY AND REHAB. RSCH., *Disability and Secondary Conditions*, in *HEALTHY PEOPLE 2010 FINAL REVIEW* 6-3, 6-3 (2012).

21. See Smeltzer, Sharts-Hopko, Ott, Zimmerman & Duffin, *supra* note 14; *DISABILITY AND SECONDARY CONDITIONS*, *supra* note 21.

22. See Smeltzer, Sharts-Hopko, Ott, Zimmerman & Duffin, *supra* note 14; *DISABILITY AND SECONDARY CONDITIONS*, *supra* note 21.

23. See Smeltzer, Sharts-Hopko, Ott, Zimmerman & Duffin, *supra* note 14; *DISABILITY AND SECONDARY CONDITIONS*, *supra* note 21.

24. See generally ERVING GOFFMAN, *STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY* (1986).

overlooked within medicine. Section II analyzes the othering<sup>25</sup> effect on women with non-apparent disabilities. To address this, the dilemma of difference is discussed. Section III discusses the U.S. healthcare system, the dangers of diagnostic error, and the influence of implicit and explicit bias<sup>26</sup> on the health of women with disabilities. This section also considers the dangers posed to these women, and broader considerations for society and the functioning of healthcare. Specifically, this section reveals the grave costs of error to society and to the healthcare business; it is imperative to reduce error rates to better protect patients and protect healthcare as an industry. Section IV explores relevant legal theories and frameworks. This section uses intersectionality<sup>27</sup> to explain the different identities in which women with disabilities are viewed. Further, it analyzes disability anti-discrimination to reveal the misguided ways the law over-relied on the able-bodied standard. The next section introduces recommendations and emphasizes the need for an ideological shift on how society views women with disabilities. From here, additional recommendations include recognizing the importance that a patient is an active participant in their care and improving communication between healthcare providers and vulnerable populations. Finally, this paper concludes with next steps and considerations for the future.

## I. HISTORY OF WOMEN IN MEDICINE

*“Perfect health is a priceless blessing to all, but it means even more to women than to men.”<sup>28</sup>*

*- Thomas Smith Clouston*

Clouston was an eminent Victorian doctor, and his words reflect the idea that the health of women has limited them, and these limitations were often more burdensome than on men.<sup>29</sup> Medical literature during the British Victorian era

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25. Angélica Guevara, *The Need to Reimagine Disability Rights Law Because the Medical Model of Disability Fails Us All*, 2021 WISC. L. REV. 269, 285 (2021)

26. See generally Dayna Bowen Matthew, *Toward A Structural Theory of Implicit Racial and Ethnic Bias in Health Care*, 25 HEALTH MATRIX 61 (2015).

27. See generally Kimberle Crenshaw, *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics*, 1989 U. CHI. L.F. 139, 149 (1989).

28. T.S. CLOUSTON, *FEMALE EDUCATION FROM A MEDICAL POINT OF VIEW* 41 (1882).

29. Lyndsey Jenkins, *Disability and the Perpetually Unwell Woman in Late Victorian Medical Literature*—by Lucy McCormick, WOMEN’S HEALTH NETWORK (Jan. 30, 2023), <https://perma.cc/UL6U-U25H>.

reflected women as being in a perpetual state of poor health.<sup>30</sup> During Victorian times, men held nearly all positions of power and as such, the male body became seen as the ideal to equip and prepare someone for such power.<sup>31</sup> Common bodily functions such as menstruation and pregnancy were seen as weak—further solidifying the idea that women were simply an unhealthy version of men.<sup>32</sup> Through this lens, to be a woman meant to be unwell.<sup>33</sup> Clouston, in a few short words, helps to sum up the challenges faced by women not only in terms of their bodies, but also how they live, how they are perceived, their role in society, and whether they are capable.<sup>34</sup>

Women continue to be overlooked in medicine.<sup>35</sup> Throughout history, medical education and research have been male-focused, specifically on the white cisgendered male.<sup>36</sup> Within medicine a foundation exists of research conducted on the white male with the assumption that this data could simply be extrapolated to women and other racial and ethnic minorities.<sup>37</sup> After all, women were merely weak versions of men.<sup>38</sup> Contrary to this flawed assumption, research has found sex-based differences to be an important variable that affects health and illness.<sup>39</sup> Research has revealed evidence of significant sex differences in various bodily functions, including those of the liver, kidneys, and the digestive system.<sup>40</sup> How the female body responds to a disease or reacts to treatment will likely be different than men.<sup>41</sup> Consequently, it is not enough to study white cisgendered men in medicine and assume the findings are applicable to women, the transgender population, or other racial groups.<sup>42</sup>

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30. *Id.*

31. *Id.*

32. *Id.*

33. *Id.*

34. *Id.*

35. Bridget Balch, *Why we know so little about women's health*, AAMC (Mar. 26, 2024), <https://perma.cc/S9HL-QVRL>.

36. Rebecca Dresser, *Wanted Single, White Male for Medical Research*, 22 HASTINGS CTR. REP. 24, 24 (1992).

37. *Id.*

38. Jenkins, *supra* note 29.

39. See generally Emmanuel O. Fadiran & Lei Zhang, *Effects of Sex Differences in the Pharmacokinetics of Drugs and Their Impact on the Safety of Medicines in Women*, 41 MEDICINES FOR WOMEN (Mira Harrison-Woolrych ed., 2015); Comm. on Understanding Bio. of Sex & Gender Differences, Inst. of Med., *Sex Begins in the Womb*, 45 EXPLORING THE BIOLOGICAL CONTRIBUTIONS TO HUMAN HEALTH: DOES SEX MATTER? (Theresa M. Wizemann & Mary-Lou Pardue eds., 2001) [hereinafter DOES SEX MATTER?].

40. DOES SEX MATTER?, *supra* note 35 at 72 (discussing differences in sex and effects on health care: “[W]omen, but not men, undergo fluctuations associated with the reproductive condition (such as the ovarian cycle and pregnancy) that influence numerous bodily functions (e.g., gastrointestinal transit time, urinary creatinine clearance, liver enzyme function, and thermo-regulation), including brain function.”).

41. *See id.* at 2.

42. Dresser, *supra* note 36; ELINOR CLEGHORN, UNWELL WOMEN: MISDIAGNOSIS AND MYTH IN A MAN-MADE WORLD 20 (Dutton 2021); Phoebe Jean-Pierre, *Why Medical Error is Killing You (and Everyone Else)*, 57 U. MICH. J.L. REFORM 481 (2024); Phoebe Jean-Pierre, *Justice Denied: Examining Implicit Bias, Vulnerable Communities, the Legal System, and Diagnostic Errors*, 15 ALA. C.R. & C.L. L. REV. 181 (2023).

Physicality sets women apart from men. Women are frequently seen as weaker and incapable.<sup>43</sup> Historical texts about puberty demonstrate that these changes in women rather than natural are an “inherent impairment of having a female body.”<sup>44</sup> Maturing as a woman and into the female body—limited a woman’s capabilities.<sup>45</sup> Puberty in women was frequently associated with suffering and abnormality.<sup>46</sup> Healthy normal changes in the female form were deemed as a state of ill health that would burden the woman for the rest of her life.<sup>47</sup> Women were assumed to be more delicately composed, and thus, it was believed they were predisposed to a number of pathological conditions.<sup>48</sup>

Emotions are another consideration that sets women apart from men and results in them being seen as less than, out of control,<sup>49</sup> or unable to make decisions for their health, well-being, or bodies.<sup>50</sup> This framework can be surmised with the concept of hysteria, which is characterized by uncontrollable emotion and irrationality.<sup>51</sup> In healthcare, under hysteria, women are seen as not only overly emotional, but also incapable of discussing or taking care of their own bodies.<sup>52</sup> The perceived irrationality and excessive emotionality of hysteria have also been deemed a disability.<sup>53</sup>

Further, the ostracization and treatment of women in healthcare worsened if the woman had a disability. A woman’s unhealthiness was used to justify marginalizing her from society.<sup>54</sup> Disabilities were used to “clarify and define who deserved, and who was deservedly excluded from citizenship.”<sup>55</sup> In the medical sense, disability was also used as a tool to oppress women due to their bodily and physiological differences from men.<sup>56</sup>

Though society has moved forward, women patients—especially those with disabilities—continue to face numerous challenges to their health and within the healthcare system.

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43. Douglas Baynton, *Disability and the Justification of Inequality in American History*, 34 THE NEW DISABILITY HISTORY: AMERICAN PERSPECTIVES 57 (Paul Longmore & Lauri Umansky eds., 2001).

44. See Jenkins, *supra* note 29.

45. *Id.*

46. CHARLES BINGHAM PENROSE, A TEXT-BOOK OF DISEASES OF WOMEN 20 (4th ed. 1902).

47. See Jenkins, *supra* note 29; *id.*

48. See Jenkins, *supra* note 29; PENROSE, *supra* note 42 at 20.

49. Phoebe Jean-Pierre, *The Misdiagnosis of Women: Female Hysteria, Diagnostic Errors, and Legal Implications*, S. CAL. REV. L. & SOC. JUST. (forthcoming 2025).

50. See *Id.*; CLEGHORN, *supra* note 38 at 20.

51. See Cecilia Tasca, Mariangela Rapetti, Mauro Giovanni Carta, & Bianca Fadda, *Women and Hysteria in the History of Mental Health*, 8 CLIN. PRAC. & EPIDEMIOLOGY MENTAL HEALTH 110, 110 (2012); see *The History of Hysteria and How it Impacts You*, PLANNED PARENTHOOD OF FLORIDA (April 9, 2025), <https://perma.cc/UAC3-JQ49>.

52. See Jean-Pierre, *supra* note 44.

53. See Baynton, *supra* note 39, at 43.

54. See Jenkins, *supra* note 29.

55. See Baynton, *supra* note 39, at 33.

56. CAROL THOMAS, *FEMALE FORMS: EXPERIENCING AND UNDERSTANDING DISABILITY* 40 (1999) (“Disability, like patriarchy is a form of social oppression.”).

### A. TRADITIONAL PERSPECTIVES OF MEDICINE

*“How did white males come to be the prototype of the human research subject? Whether misplaced chivalry or tacit assumption of a human norm, the exclusion of women and nonwhite minorities is a glaring mistake.”<sup>57</sup>*

Historically, the white male cis-gendered body has been at the center of health-care. white men, as the primary and overrepresented subjects in clinical trials, testing, and care, have largely dominated the healthcare space. Much of what we know about medicine is based on the white male body.<sup>58</sup> According to the National Institutes of Health (NIH), this practice of centralizing the White male body “has resulted in significant gaps in [our] knowledge” of how diseases affect both men and women.<sup>59</sup> In short, white men are not a proxy for how other patients experience disease or health concerns in the U.S. medical system.

In June 1990, congressional investigators shared a shocking report<sup>60</sup> finding that women continued to be significantly underrepresented<sup>61</sup> in biomedical research study populations despite a 1986 federal policy to the contrary.<sup>62</sup> A failure to include women in research populations occurs across the board.<sup>63</sup> Numerous studies—including research sponsored by the NIH<sup>64</sup>—reflect that cardiovascular disease has been exclusively studied in men.<sup>65</sup> The lack of sufficient research on women is likely why heart disease remains one of the top killers of women.<sup>66</sup>

However, heart disease is only *one* instance where women’s health suffers.<sup>67</sup> The first two decades of a major federal study on health and aging included only men.<sup>68</sup> This is particularly problematic given that nearly two-thirds of the elderly

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57. Dresser, *supra* note 38 at 24.

58. See Ruqaiijah Yearby, *Race based medicine, colorblind disease: how racism in medicine harms us all* 21 THE AM. J. OF BIOETHICS 19, 23 (2021).

59. See *Id.* at 24; *National Institutes of Health: Problems in Implementing Policy on Women in Study Populations: Hearing before the H. Subcomm. on Hous. & Consumer Int. of the H. Comm. on Aging*, 101 Cong.2 1990 (statement of Mark v. Nadel, Assoc. Dir., Nat'l & Pub. Health Iss., Hum. Res. Div.). This is problematic as what works for White men often does not work for women, racial and ethnic minorities, and the LGBTQIA+ and transgender population.; Phoebe Jean-Pierre, *Medical Error and Vulnerable Communities*, 102 Bos. U. L. Rev. 327 (2022) [hereinafter *Medical Error and Vulnerable Communities*]; Phoebe Jean-Pierre, *Why Medical Error Is Killing You (And Everyone Else)*, 57 U. MICH. J. L. REFORM 481 (2024).

60. See Dresser, *supra* note 38.

61. *Id.*

62. *Id.*

63. *Id.*

64. *Id.*

65. *Id.*; see CLEGHORN, *supra* note 38 at 298-99.

66. See CLEGHORN, *supra* note 38 at 299; *Heart Disease Remains Leading Cause of Death for Women: Addressing the Gender Bias in Cardiovascular Care*, CARDIOMETABOLIC HEALTH CONG. (Feb. 14, 2024), <https://perma.cc/VW4F-ZND4>.

67. See CLEGHORN, *supra* note 38 at 299.

68. See Dresser, *supra* note 38.

population is women.<sup>69</sup> Encouragement and formal guidelines from the NIH have done little to alleviate the minimal inclusion of other communities in study populations.<sup>70</sup>

The distinctions in the physiology of men and women can influence how each experiences disease and illness.<sup>71</sup> Aside from sex-linked diseases—like uterine or prostate cancer—research reveals that seemingly “gender neutral” conditions like heart disease, AIDS, depression, and others are expressed differently in men and women.<sup>72</sup> Due to the historical and continued overrepresentation of white men in research populations, physicians often lack sufficient evidence of whether women will be helped, harmed, or unaffected by the many therapies proclaiming to promote overall human health.<sup>73</sup>

## 1. Health Needs of PWD are Different

This historical focus on the White male body has translated into problems today for how other populations are perceived and treated within healthcare.<sup>74</sup> PWD experience worse health in comparison with their counterparts without disabilities.<sup>75</sup> PWD facing systems that were not designed to accommodate them, including the U.S. healthcare system,<sup>76</sup> likely contributes to these health disparities. Research also reveals that PWD are more likely than those without disabilities to report poorer health and less access to adequate care.<sup>77</sup> The CDC has also identified disability as a condition that is especially common among women.<sup>78</sup> Women with disabilities face a myriad of difficulties in the U.S. healthcare system. To start, women with disabilities are more likely to have unmet healthcare needs.<sup>79</sup> Women with chronic physical disabilities are also more likely to report poor health.<sup>80</sup> In this context, these women continue to face disparate treatment, care, and access. Women with disabilities are also more likely to experience frequent mental distress than men with disabilities.<sup>81</sup> Due to notions of female

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69. *Id.*

70. *Id.*

71. *Id.*; see also CLEGHORN, *supra* note 38 at 299.

72. Dresser, *supra* note 38.

73. *Id.*

74. See Dayna Bowen Matthew, *Toward A Structural Theory of Implicit Racial and Ethnic Bias in Health Care*, 25 HEALTH MATRIX 61, 64 (2015) (discussing how implicit bias results in health disparities and poorer health outcomes among racial and ethnic minorities); Yearby, *supra* note 54.

75. Behzad Karami Martin, Heather J. Williamson, Ali Kazemi Karyani, Satar Rezaei, Moslem Soofi, & Shahin Soltani, *Barriers in Access to Healthcare for Women with Disabilities: A Systematic Review in Qualitative Studies*, 21 BMC WOMEN’S HEALTH 1, 1 (2021).

76. Stephanie Pappas, *Despite the ADA, Equity Is Still Out of Reach*, AM. PSYCH. ASS’N (Nov. 1, 2020), <https://perma.cc/D88N-83YW>.

77. *Disability and Health Information for Health Care Providers*, CDC, <https://perma.cc/3CHY-X7QL> (Apr. 7, 2025).

78. *Supporting Women with Disabilities to Achieve Optimal Health*, CDC (July 19, 2024), <https://perma.cc/RM4B-58B3>.

79. See Matin, Williamson, Karyani, Rezaei, Soofi, & Soltani, *supra* note 71 at 1-2.

80. See *Supporting Women with Disabilities to Achieve Optimal Health*, *supra* note 74.

81. *Id.*

hysteria, mental health is an important area to explore for women with disabilities. Female hysteria poses challenges in how these women are perceived and treated for their mental distress.

## B. FEMALE HYSTERIA

*“I was always told that my pain was exaggerated and that I was making it up.”<sup>82</sup>*

*—Hannah Epstein, 17*

*“My entire sixth grade experience was people not believing that I was sick.”<sup>83</sup>*

*“After my first visit [to a physical therapist] the woman told me she knew I was lying about my pain, and it was all in my head.”<sup>84</sup>*

*—Sarah Kleppe, (now) 18*

Throughout history, science, medicine, and society have sought ways to both explain and control female emotions. “For centuries, doctors readily diagnosed women with ‘hysteria,’ an alleged mental health condition that explained away any behaviors or symptoms that made men . . . uncomfortable.”<sup>85</sup> Historically, hysteria was “the first mental disorder attributable to women.”<sup>86</sup> For hundreds of years, hysteria was used as a routine diagnosis for women, peaking during the Victorian era.<sup>87</sup> Hysteria was first described in the second millennium BC and was perceived as an exclusively female disorder until the 20<sup>th</sup> century.<sup>88</sup> The first description of hysteria dates to the ancient Egyptians, where hysterical disorders in women resulted from the spontaneous movement of the uterus around the female body.<sup>89</sup> This concept persisted among the ancient Greeks, arose in Greek mythology, and even helped form the basis of psychiatry.<sup>90</sup> Hysteria stems from the Greek word *hysterus*, which means uterus.<sup>91</sup> Similar to the Egyptians, ancient Greeks and Plato, perceived the womb as an animal that roamed all over a

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82. Bryn Healy, *Hysteria Diagnosis Still Hounds Some Girls with Invisible Disabilities*, WOMEN’S ENEWS (July, 7, 2025), <https://perma.cc/4XZ8-WW6X>.

83. *Id.*

84. *Id.*

85. Maria Cohut, *The Controversy of Female Hysteria*, MED. NEWS TODAY (Oct. 13, 2020), <https://perma.cc/3YVA-QSFK>.

86. See Tasca, Rapetti, Carta, & Fadda, *supra* note 47 at 110.

87. *Hysteria or Misogyny? Women, Madness and Mental Health*, U.S.C. VISIONS & VOICES, <https://perma.cc/4AJX-ZHJJ> (last visited Jan. 2, 2025).

88. See Tasca, Rapetti, Carta, & Fadda, *supra* note 47 at 110.

89. *Id.*

90. *Id.*

91. Jill A. Astbury, *Women’s Mental Health: From Hysteria to Human Rights*, in WOMEN’S MENTAL HEALTH: A LIFE-CYCLE APPROACH 377, 377 (Sarah E. Romas & Mary V. Seeman eds., Wolters Kluwer Health 2006).

woman's body, causing all manner of problems.<sup>92</sup> The dangers of the "wandering womb" were perceived as stronger when a woman did not have children. In general, any psychological problems faced by women were believed to be caused by the movement of the uterus all around the body.<sup>93</sup> Hysteria prevailed for various symptoms, including: shortness of breath, rebellion, and sexual desire (or lack thereof).<sup>94</sup> Describing women's health within the context of hysteria justified various mechanisms for controlling women.<sup>95</sup> Hysteria also suggested physical symptoms were *all in her head* or the product of sexual frustration.<sup>96</sup>

The treatments for this supposed hysteria and female problems ranged from "hanging women upside down and shaking them" (the idea here to return the uterus to its correct place) to placing leeches in the vagina to giving suppositories of bull urine.<sup>97</sup> Other recommended treatments included using herbs or prescribing patients to have regular sex with their husbands.<sup>98</sup> In extreme cases, hysteria could be used to justify committing a woman to an insane asylum to undergo a hysterectomy.<sup>99</sup> As outrageous as these treatments seem, the real mystery at the time was the female form. Alongside the utter confusion over the female body and how to treat hysteria—in many respects, a catchall for all unknown female health concerns—women were also "accused of madness, burned as witches, or confined to mental institutions."<sup>100</sup> Hysteria, rather than reflective of problems with the female body, serves as a "dramatic medical metaphor for everything men found mysterious or unmanageable in the opposite sex."<sup>101</sup> Over time, perspectives in medicine have shifted, and many of these antiquated beliefs have been disbanded. Unfortunately, the history and stigma of female hysteria remain. Many health disparities persist that affect the health of women.<sup>102</sup> Women suffer from "autoimmune diseases, chronic pain syndromes, and disability at higher rates than their male counterparts."<sup>103</sup> Despite this, these conditions attract and receive less funding for medical research.<sup>104</sup>

Further, hysteria created a deeply rooted history of misinformation as to the female body, how to treat female patients, and a staunch belief that women are incapable of discussing or maintaining control of their bodies.<sup>105</sup> Female hysteria

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92. See *Hysteria or Misogyny*, *supra* note 83.

93. See ASTBURY, *supra* note 87.

94. See *Hysteria or Misogyny*, *supra* note 83.

95. *Id.*

96. *Id.*

97. Isabella Backman, *From Hysteria to Empowerment*, YALE MED. MAG., Spr. 2024, Iss. 172, <https://perma.cc/F2PX-MV6>.

98. See *Hysteria or Misogyny*, *supra* note 83.

99. *Id.*

100. See BACKMAN, *supra* note 93.

101. *Id.*

102. *Id.*

103. *Id.*

104. *Id.*

105. See *The Lingering Effects of Female Hysteria in Medicine*, Berkeley Political Review (Aug. 10, 2021), <https://perma.cc/FSC4-XRQE>.

was removed from medical texts in the 1950s.<sup>106</sup> Despite this step, notions of female hysteria have created a dangerous environment of misinformation that persists to this day.<sup>107</sup> Health issues of women are frequently “dismissed, underestimated, and misdiagnosed due to a lack of widespread education on female bodies.”<sup>108</sup> The poorer treatment experienced by female patients is only exacerbated when considering other demographic characteristics, such as: disability, race, socioeconomic status, or age.<sup>109</sup>

Women with disabilities experience greater disparities in access to healthcare.<sup>110</sup> Some of the common barriers to access are attitudes, stereotypes, and misperceptions about PWD.<sup>111</sup> Unfortunately, alongside conceptions of female hysteria, women with disabilities also contend with stigma and the ways they are viewed and othered within the healthcare system. “Women with disabilities hold at least two stereotyped identities, each subject to prejudice, stigma, and oppression.”<sup>112</sup> The following section emphasizes the concept of stigma and the ways that women with disabilities are othered and seen as less than within healthcare.

### C. STIGMA AND MISPERCEPTIONS OF WOMEN IN HEALTHCARE

*Something had to be done to remove the stigma.*<sup>113</sup>

Stigma relates to how some individuals are viewed as the *other* and how they are treated in society, but it also provides a unique framework to view health and disparate treatment in legal and healthcare systems. Stigma results in widespread social disapproval and devaluation of individuals viewed as the *other*.<sup>114</sup> Individuals with an attribute that others consider negative—like a disability—are seen as unfavorable or unacceptable.<sup>115</sup> Stigma is a term widely used throughout society, and it characterizes the experiences of many individuals with disabilities. A poignant letter published in Erving Goffman’s book, *Notes on the Management*

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106. *Id.*

107. *Id.*

108. *Id.*

109. *Id.*

110. See *Supporting Women with Disabilities to Achieve Optimal Health*, *supra* note 76; See generally PAPPAS, *supra* note 72.

111. See *Supporting Women with Disabilities to Achieve Optimal Health*, *supra* note 76.

112. Rhoda Olkin, H’Sien Hayward, Melody Schaff Abbene & Goldie VanHeel, *The Experiences of Microaggressions Against Women with Visible and Invisible Disabilities*, 75 J. SOC. ISSUES 757 (2019).

113. Imogen Tyler, *Resituating Erving Goffman: From Stigma Power to Black Power*, 66 SOCIO. REV. 744 (2018).

114. See Brenda Major & Laurie T. O’Brien, *The Social Psychology of Stigma*, 56 ANN. REV. PSYCH. 393 (2005); ERVING GOFFMAN, *STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY* (1986); Shirli Werner, *Public Stigma in Intellectual Disability: Do Direct Versus Indirect Questions Make a Difference?*, 59 J. INTELL. DISABILITY RSCH. 958 (2015).

115. See MAJOR & O’BRIEN, *supra* note 110; GOFFMAN, *supra* note 110; WERNER, *supra* note 110.

*of a Spoiled Identity*, provides a helpful example to introduce the concept of stigma. In this letter, a 16-year-old girl laments being born without a nose. She describes concerns such as being unable to get a boyfriend and scaring others with her visage. Her heartfelt confession takes a dark turn as she contemplates suicide; such is the power of stigma:

Dear Miss Lonelyhearts—

*I am sixteen years old now and I dont know what to do and would appreciate it if you could tell me what to do. When I was a little girl it was not so bad because I got used to the kids on the block makeing fun of me, but now I would like to have boyfriends like the other girls and go out on Saturday nites, but no boy will take me because I was born without a nose— although I am a good dancer and have a nice shape and my father buys me pretty clothes.*

*I sit and look at myself all day and cry. I have a big hole in the middle of my face that scares people even myself so I cant blame the boys for not wanting to take me out. My mother loves me, but she crys terrible when she looks at me.*

*What did I do to deserve such a terrible bad fate? Even if I did do some bad things I didn't do any before I was a year old and I was born this way. I asked Papa and he says he doesnt know, but that maybe I did something in the other world before I was born or that maybe I was being punished for his sins. I dont believe that because he is a very nice man. Ought I commit suicide?*

*Sincerely yours, Desperate*<sup>116</sup>

The concept of stigma originated among the ancient Greeks, who used the term to “refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier.”<sup>117</sup> For the Greeks, stigma designated a mark on the body—such as a tattoo or a scar.<sup>118</sup> Individuals who bore such marks were cast out of society and were viewed as part of a stigmatized group.<sup>119</sup> As in the example with Desperate, the lack of a nose is a physical symbol of her difference.<sup>120</sup> However, for those with non-apparent disabilities, there is not an absence of a nose or a “missing” limb but, instead, the inability to fulfill a behavior that has been established as the norm. In fact, today, stigma is viewed more in a

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116. See GOFFMAN, *supra* note 110.

117. *Id.* at 1.

118. *Id.*; Bruce L. Lambert, *Stigma, Part 1: Explaining Goffman's Idea of Spoiled Identity*, HOW COMM'C'N WORKS (Dec. 16, 2020), <https://perma.cc/6EDD-2QXR>.

119. See LAMBERT, *supra* note 114.

120. See GOFFMAN, *supra* note 112.

metaphorical sense—as though there is a metaphorical stain or mark on a person’s identity.<sup>121</sup> Broadly, stigma “connotes a mark of disapproval: that can be both non-apparent or apparent and allows insiders to identify and disassociate from outsiders.”<sup>122</sup> Stigma is also a social phenomenon that maintains roots in social structures.<sup>123</sup>

A person cannot understand what it means to be stigmatized or carry a stigma unless a person also understands what is normal.<sup>124</sup> Stigma and normalcy remain at opposite ends of a spectrum regarding the nature of one’s identity and how that identity is formed.<sup>125</sup> “Stigmatized people are always stigmatized in relation to some group of people who are normal, and normal people are always normal in relation to some people who are less than normal or stigmatized.”<sup>126</sup> There can be no normal or acceptability without specific examples of what is abnormal or unacceptable.<sup>127</sup> Similarly, women with disabilities are stigmatized because they are being compared against the male able-body as the norm.<sup>128</sup> Women with disabilities are not only stigmatized socially, but this spills over into healthcare, where they are othered. Treatment and perception of women with disabilities in healthcare is a widespread problem.<sup>129</sup> This population suffers from poorer treatment, worse outcomes, and extensive influences of stigma and othering.<sup>130</sup>

## II. OTHERING

Women with non-apparent disabilities are not often discussed in healthcare. This section highlights the barriers that women with non-apparent disabilities must endure in healthcare. Women are first unseen by doctors who ignore the seriousness of their medical concerns by deeming them “emotional” or “hysterical.”<sup>131</sup> These women are again not believed once the non-apparent disability appears or is disclosed.<sup>132</sup> Historically, similar to how women were treated and

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121. See LAMBERT, *supra* note 116.

122. Graham Scambler, *Health-Related Stigma*, 31 SOCIO. HEALTH ILLNESS 441 (2009).

123. Mark L. Hatzenbuehler, *Introduction to the Special Issue on Structural Stigma and Health*, 103 SOC. SCI. & MED. 1 (2014).

124. See LAMBERT, *supra* note 115.

125. *Id.*

126. *Id.*

127. See SCRAMBLER, *supra* note 118.

128. See Sarah Heiss, *Locating the Bodies of Women and Disability in Definitions of Beauty: An Analysis of Dove’s Campaign for Real Beauty*, 31 Disability Stud. Q. 1 (2011), <https://perma.cc/LMG2-QKJW>.

129. See Behzad Karami Matin, Heidi J. Williamson & Ali Kazemi Karyani, *Barriers in Access to Healthcare for Women with Disabilities: A Systematic Review in Qualitative Studies*, 21 BMC Women’s Health 44 (2021), <https://perma.cc/4DG3-SY45>.

130. *Id.*

131. See Anna Samulowitz, Erik Gremyr, Bo Eriksson & Gunnel Hensing, “*Brave Men*” and “*Emotional Women*”: A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms Toward Patients With Chronic Pain, 16 PAIN RES & MANAGEMENT 1 (2018), <https://perma.cc/T7G9-6DQX>.

132. See Rhoda Olkin, Michelle Hayward, Nicole Abbott, & Stephanie B. Berkowitz, *The Experiences of Microaggressions Against Women with Visible and Invisible Disabilities*, 75 J. Soc. ISSUES 757 (2019).

seen in society, those with non-apparent disabilities were also stigmatized and treated as the “other.” To perpetuate othering, some people with non-apparent disabilities were labeled mad.<sup>133</sup>

Martha Minow, a leading disability legal scholar, calls attention to “the dilemma of difference,” describing how “[t]he stigma of difference may be re-created by both ignoring and by focusing on [the disability].”<sup>134</sup> In essence, women with non-apparent disabilities in need of treatment or who are misdiagnosed must advocate for themselves by highlighting their illness. To receive services or benefits, the disability is highlighted, while the claimant is simultaneously yearning for equal treatment and attempting to avoid feeling like the “other.”<sup>135</sup> Eradicating the stigma and reimagining other alternatives to reduce discrimination and health disparities start by shifting the focus away from an individual’s abilities and focusing instead on how society (in this instance the US healthcare system) disables.<sup>136</sup>

In exploring the intersection of gender and disability, to do no harm means understanding how women with disabilities differ from other women.<sup>137</sup> The reality is that there are women who face health disparities due to their gender, but without the added layer of disability,<sup>138</sup> which becomes more challenging.

The othering of women and people with disabilities leads to diagnostic errors. At face value, when a doctor is dismissive of female patients, the doctor may also simultaneously ignore a non-apparent disability. The following section will focus on the role of healthcare, diagnostic errors, and the resulting harms. The healthcare system is a major business in the U.S., but it is plagued by patient harm and medical error. This is problematic as it creates unsafe systems, places patients at risk, and is incredibly costly. While any patient can be exposed to harm or error within the healthcare system, research has revealed that certain populations and communities are more likely to suffer harm.<sup>139</sup> Women with disabilities compose a large portion of patients and they are also a vulnerable population—making it more likely that they will be exposed to error and harm. The harm is not only

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133. See Sylvia Freedman, *Do Mad People Get Endometriosis or Does Endo Make You Mad?*, The Guardian (Mar. 21, 2017), <https://perma.cc/V8WJ-WDMZ>.

134. MARTHA MINOW, *MAKING ALL THE DIFFERENCE: INCLUSION, EXCLUSION, AND AMERICAN LAW* 20 (1990).

135. Angélica Guevara, *The Need to Reimagine Disability Rights Law Because the Medical Model of Disability Fails Us All*, 2021 WISC. L. REV. 269, 276 (2021); See WENDELL, *supra* note 129.

136. See Angélica Guevara, *The Need to Reimagine Disability Rights Law Because the Medical Model of Disability Fails Us All*, 2021 WISC. L. REV. 269, 276 (2021).

137. Jennifer P. Wisdom et al, *Health Disparities Between Women with and Without Disabilities: A Review of the Research*, 25 SOC. WORK & PUB. HEALTH 368 (2010).

138. *Id.*

139. Glenn Flores & Emmanuel Ngui, *Racial/Ethnic Disparities and Patient Safety*, 53 PEDIATRIC CLIN. N. AM. 1197 (2006); L. Ebony Boulware, Lisa A. Cooper, Lloyd E. Ratner, Thomas A. LaVeist, Neil R. Powe, *Race and Trust in the Health Care System*, 118 PUB. HEALTH REP. 358, 362–64 (2003); Phoebe Jean-Pierre, *Why Medical Error is Killing You (and Everyone Else)*, 57 U. MICH. J.L. REFORM 481 (2024); Phoebe Jean-Pierre, *Justice Denied: Examining Implicit Bias, Vulnerable Communities, the Legal System, and Diagnostic Errors*, 15 ALA. C.R. & C.L. L. REV. 181 (2023).

detrimental for this population, but it also places strain on the healthcare system and society more broadly.

### III. HEALTHCARE, DIAGNOSTIC ERROR, AND HARM

*“Diagnostic errors occur more commonly than other kinds of errors, they are more likely to harm patients, and they are more likely to be preventable.”<sup>140</sup>*

For years, the U.S. healthcare system has continued to function with a major shortcoming: diagnostic error.<sup>141</sup> Diagnostic errors refer to missed, delayed, or incorrect diagnoses, and they remain pervasive in all areas of care and at all levels within the U.S. healthcare system.<sup>142</sup> Providing the correct diagnosis is critical. The diagnosis provides an explanation of the patient’s health problem. Further, diagnosis influencing healthcare decisions and how providers decide to treat the patient.<sup>143</sup> Unfortunately, diagnostic errors threaten patient health and mental state.<sup>144</sup> Diagnostic errors can lead to negative health outcomes and psychological distress.<sup>145</sup> Additionally, diagnostic errors are financially costly,<sup>146</sup> representing the leading cause of malpractice claims, and serve as the leading cause of preventable adverse outcomes.<sup>147</sup> Diagnostic errors may also expose patients to inappropriate or unnecessary treatment.<sup>148</sup> In the alternative, appropriate—and even lifesaving—treatment may be withheld or delayed due to the error in the initial diagnosis.<sup>149</sup> Despite the great risk of harm to patients, efforts to identify and address diagnostic errors have been limited.<sup>150</sup> The lack of attention to the risks posed by diagnostic errors is significant—as “most people will experience at least one diagnostic error in their lifetime, sometimes with devastating consequences.”<sup>151</sup>

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140. James W. Ely, Laurence C. Kaldjian & Donna M. D’Alessandro, *Diagnostic Errors in Primary Care: Lessons Learned*, 25(1) J. AM. BD. FAM. MED. 87 (2012).

141. COMM. ON DIAG. ERROR IN HEALTH CARE, BD. ON HEALTH CARE SERVS., INST. OF MED., NAT’L ACAD. OF SCI., ENG’G, & SCI., IMPROVING DIAGNOSIS IN HEALTH CARE 19 (Erin P. Balogh et al. eds., 2015) [hereinafter IMPROVING DIAGNOSIS IN HEALTH CARE].

142. *Id.*

143. *Id.*

144. *Id.*

145. *Id.* at 19.

146. *Id.*

147. Mario Plebani, *Diagnostic Errors and Laboratory Medicine—Causes and Strategies*, 26 EJIFCC 7 (2015); Ali S. Saber Tehrani et al., *25-Year Summary of US Malpractice Claims for Diagnostic Errors 1986–2010: An Analysis from the National Practitioner Data Bank*, 22 BMJ QUALITY & SAFETY 672 (2013); Hardeep Singh et al., *Types and Origins of Diagnostic Errors in Primary Care Settings*, 173 JAMA INTERNAL MEDICINE 418 (2013).

148. See IMPROVING DIAGNOSIS IN HEALTH CARE, *supra* note 125, at 19.

149. *Id.*

150. *Id.*

151. *Id.*

Though all patients may be exposed to diagnostic error, certain communities are more likely to suffer harm.<sup>152</sup> Women and people with disabilities are more likely to experience a diagnostic error, leading to poorer health outcomes, greater health disparities,<sup>153</sup> and significant financial costs to society and the healthcare system.<sup>154</sup>

#### A. CHALLENGES TO HEALTHCARE

Healthcare plays a major role in society and is one of the most essential parts of the U.S. economy. Healthcare is an industry that supports most Americans through their lives, from childbirth to encouraging longevity with continued support and management of health, and ultimately handling end-of-life care and death. Healthcare is essential, both individually and collectively for the U.S. population. Despite this, healthcare is still just a business—a big business. In 2019, there were 22 million healthcare workers in the U.S.<sup>155</sup> The healthcare industry is one of the largest and fastest-growing sectors and accounts for 10.8% of all U.S. workers as of 2023.<sup>156</sup>

Given its prominence throughout our lives and the sheer size of the workforce, the healthcare industry occupies a large sector of the business world. However, being a big business does not make healthcare infallible. Rather, the healthcare sector is plagued by a costly and *deadly* problem—medical error. *Preventable* medical errors are one of the leading causes of death in medical settings in the U.S.<sup>157</sup> and present a major challenge in healthcare. Though a problem for all patients, women experience greater exposure to error.<sup>158</sup> Estimates put women at as much as 30% more likely to experience a medical error.<sup>159</sup> More errors mean more money. Since women are at greater risk of experiencing an error, it costs

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152. Glenn Flores & Emmanuel Ngui, *Racial/Ethnic Disparities and Patient Safety*, 53 PEDIATRIC CLINICS N. AM. 1197 (2006); L. Ebony Boulware, Lisa A. Cooper, Lloyd E. Ratner, Thomas A. LaVeist, Neil R. Powe, *Race and Trust in the Health Care System*, 118 PUB. HEALTH REP. 358, 362-64 (2003); Phoebe Jean-Pierre, *Why Medical Error is Killing You (and Everyone Else)*, 57 U. MICH. J.L. REFORM 481 (2024); Phoebe Jean-Pierre, *Justice Denied: Examining Implicit Bias, Vulnerable Communities, the Legal System, and Diagnostic Errors*, 15 ALA. C.R. & C.L. L. REV. 181 (2023).

153. Jean-Pierre, *supra* note 45.

154. *See Id.*

155. Lynda Laughlin et al., *22 Million Employed in Health Care Fight Against COVID-19*, U.S. CENSUS BUREAU (Apr. 5, 2021), <https://perma.cc/A4AE-UYLK>.

156. *Id.*

157. *See* Martin A. Makary & Michael Daniel, *Medical Error—A Leading (but Hidden) Cause of Death*, 353 BRIT. MED. J. 236, 236-37 (2016) (estimating that medical error is the third leading cause of death in the United States based on statistical calculations suggesting a mean rate of 251,454 deaths from medical error per year between 1999 and 2013).

158. Liz Szabo, *Medical mistakes are more likely in women and minorities*, NBC NEWS (Jan. 15, 2024), <https://perma.cc/5FCH-4ZTF> (discussing BMJ Quality & Safety study, “Burden of serious harms from diagnostic error in the USA” and quoting lead author Dr. David Newman-Toker on the study’s finding that “[w]omen and racial and ethnic minorities are 20% to 30% more likely than white men to experience a misdiagnosis.”).

159. *Id.*

more money to address this harm. This money can be used in other ways, including creating safer systems for patients, reducing the occurrence of errors, and decreasing the likelihood of medical malpractice lawsuits. Reducing women's exposure to preventable harm would save money, create safer systems overall for all patients, and improve the quality of care.

Quality care is expensive—but fatalities and harm to patients due to error are even more costly.<sup>160</sup> For over four decades, hospitals have been seeking ways to improve overall quality and operational efficiency<sup>161</sup> while simultaneously cutting costs. Despite best efforts, healthcare remains expensive, inefficient, and costly for patients, hospitals, the healthcare business, and the broader society.<sup>162</sup>

## B. DIAGNOSTIC ERRORS – THE NUMBERS

*“Medical misdiagnosis for women continues to be a significant problem, leading to disparate health outcomes.”<sup>163</sup>*

Gender and disability aside, diagnostic errors pose a unique and consistent threat to patient safety.<sup>164</sup> Diagnostic errors refer to missed, delayed, or incorrect diagnoses.<sup>165</sup> Here are some key statistics that highlight the extensive dangers posed by diagnostic errors:

- At least 1 in 20 U.S. adults experiences a diagnostic error each year.<sup>166</sup>
- 12 million adults in the U.S. are misdiagnosed every year.<sup>167</sup>
- Nearly 1 in 15 hospital patients who died had experienced a diagnostic error.<sup>168</sup>
- Nearly 18% of misdiagnosed patients were harmed or died.<sup>169</sup>

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160. Charles Andel et al., *The Economics of Health Care Quality and Medical Errors*, 39 J. HEALTH CARE FIN. 39 (2012).

161. *Id.* at 1.

162. Cost of Caring, “The Cost of Caring: Challenges Facing America’s Hospitals in 2025,” American Hospital Association, April 2025, <https://perma.cc/L3Y5-JG47>.

163. Jessica Thompson & Denise Blake, *Women’s Experiences of Medical Miss-Diagnosis: How Does Gender Matter in Healthcare Settings?*, 34 WOMEN’S STUD. J. 22 (2020).

164. Hardeep Singh, Ashley Meyer, and Eric Thomas, *The Frequency of Diagnostic Errors in Outpatient Care: Estimations from Large Observational Studies Involving US Adult Populations*, 23 BMJ QUAL. SAFETY 727 (2014).

165. See IMPROVING DIAGNOSIS IN HEALTH CARE, *supra* note 130; Gordon D. Schiff et al., *Diagnostic Error in Medicine: Analysis of 583 Physician-Reported Errors*, 169 ARCHIVES INTERNAL MED. 1881, 1881 (2009); Julie Abimanyi-Ochom, Shalika Bohingamu Mudiyanselage, Max Catchpool, Marnie Firipis, Sithara Wanni Arachchige Dona, and Jennifer J. Watts, *Strategies To Reduce Diagnostic Errors: A Systematic Review*, 19 BMC MED. INFORMATICS & DECISION MAKING (2019); Ekaterina Bakradze & Ava L Liberman, *Diagnostic Error in Stroke—Reasons and Proposed Solutions*, 20 CURRENT ATHEROSCLEROSIS RPTS. 11, 11 (2018).

166. See Singh, Meyer, and Thomas, *supra* note 165.

167. *Id.*

168. Andrew D. Auerbach, Tiffany M. Lee, Colin C. Hubbard, Suman R. Ranji, Katie Raffel, Gilmer Valdes John Boscardin, Anuj K. Dalal, Alyssa Harris, Ellen Flynn, Jeffrey L. Schnipper I., *Diagnostic Errors in Hospitalized Adults Who Died or Were Transferred to Intensive Care*, 84 JAMA INTERNAL MED. 164 (2024).

169. *Id.*

Despite the high rates of diagnostic errors, some patients are at higher risk than others.<sup>170</sup> Unfortunately, patient care and exposure to error is influenced by physical characteristics like race, age, or gender.<sup>171</sup> Women and racial and ethnic minorities are 20-30% more likely to experience a diagnostic error than white men.<sup>172</sup> Misdiagnosis is not just a medical error, but rather, it is a great public health concern—one that results in countless deaths and harm to women.<sup>173</sup>

The following section will explore the significant costs that diagnostic errors impose. Cost is often described as financial harm or a loss—and diagnostic errors are financially costly. Alongside this financial harm, diagnostic errors may result in different costs to society, including: physical, societal, and even human cost.

## 1. Cost of Diagnostic Error

*“[D]iagnostic errors are a significant and common challenge in health care and most people will experience at least one diagnostic error in their lifetime.”<sup>174</sup>*

Increased attention has been brought to medical errors over the past two-and-a-half decades. Diagnostic errors pose an incredible drain on human life and societal resources, yet remain largely ignored in patient safety and quality efforts.<sup>175</sup> The concern is that diagnostic errors are easy to ignore and they represent a problem that is largely hidden, as “diagnostic errors are rarely evident when they occur.”<sup>176</sup> Instead, they surface later, long after the initial misdiagnosis has resulted in harm.<sup>177</sup> Imagine an iceberg where much of its mass is unseen beneath the surface. In healthcare, this great mass under the surface represents diagnostic errors—a grave patient harm hidden at the bottom of the iceberg that is patient safety. Hidden, missed, delayed, or incorrect diagnoses are a critical area of patient safety and greatly affect healthcare quality.<sup>178</sup> As a cost savings measure, diagnostic errors have gone relatively unaddressed by the healthcare industry.<sup>179</sup> Avoiding diagnostic errors to save money is a misnomer, as diagnostic errors are both frequent and costly.<sup>180</sup> Data from malpractice claims indicates that

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170. See *id.*; *Medical Error and Vulnerable Communities*, *supra* note 55; *Data Analysis Reveals Common Errors That Prevent Patients from Getting Timely, Accurate Diagnoses*, ECRI (Sept. 5, 2024), <https://perma.cc/67RC-7UQM>.

171. Chloë FitzGerald & Samia Hurst, *Implicit Bias in Healthcare Professionals: A Systematic Review*, 18 *BMC MED. ETHICS* 1 (2017).

172. See Szabo, *supra* note 159

173. See *id.*; Jean-Pierre, *supra* note 43.

174. See *IMPROVING DIAGNOSIS IN HEALTH CARE*, *supra* note 138.

175. *Id.*

176. John S. Lam, Ed. Comment, *Hip Joint Pathology Among Men Referred to Urology for Chronic Orchialgia: A Source for Misdiagnosis and Opportunity for Quality Improvement*, 146 *UROLOGY* 1, 100 (2020).

177. *Id.*

178. *Id.*

179. *Id.*

180. *Id.*

diagnostic errors are the “most common, most costly and most dangerous” type of medical error for both inpatients and outpatients.<sup>181</sup> Each year, over 12 million Americans experience a diagnostic error.<sup>182</sup> Among these errors, one-half will seriously harm the patient.<sup>183</sup> Diagnostic failures in U.S. hospitals result in the death of 40,000-80,000 patients each year.<sup>184</sup> Other research suggests even greater risks to patients, with one study estimating that 795,000 patients a year die or become permanently disabled due to misdiagnosis.<sup>185</sup>

Diagnostic errors are costly in terms of human life, but they also drive-up hospital costs.<sup>186</sup> Estimates indicate that *each year*, diagnostic errors cost the U.S. healthcare system over \$1 billion upwards of \$100 billion.<sup>187</sup> Failures in diagnosis result in the treatment of sicker patients—individuals who experience more difficult and advanced disease progression. Diagnostic delays or mistakes may also result in “the overuse of unnecessary, expensive diagnostic tests.”<sup>188</sup> Diagnostic errors are difficult to assess, but often, when they occur healthcare responds poorly.

Alongside the danger of diagnostic error, vulnerable populations—like women with disabilities—must also contend with bias in the healthcare process. The following section details the way implicit and explicit bias influences the health and treatment of vulnerable patients.

### C. DIAGNOSTIC ERROR & BIAS

Bias and discrimination are a “structural problem” in the U.S. healthcare system.<sup>189</sup> Implicit bias refers to unconscious attitudes that can influence our judgments, decisions, and behaviors. Under explicit bias, individuals are aware of their prejudices and attitudes towards certain groups and may retain an intent to cause harm. Both forms of bias can be harmful: the potential harm done by implicit bias is unconscious, while with explicit bias the harm is known. Implicit attitudes and biases are dangerous—and can destroy the health of entire communities.

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181. Plebani, *supra* note 144.

182. See Singh, Meyer, and Thomas, *supra* note 165.

183. *Id.*

184. Jacqueline Renfrow, *1 in 3 misdiagnoses results in serious injury or death: study*, FIERCE HEALTHCARE (Jul. 11, 2019), <https://perma.cc/PRM6-2EVB>, (referencing a study conducted by the Johns Hopkins University School of Medicine that cited data, confirming that misdiagnosis is the number one serious cause of serious medical errors and that “estimated 40,000 to 80,000 deaths occur each year in U.S. hospitals related to misdiagnosis.”).

185. See Newman-Toker, Nassery, Schaffer, Yu-Moe, Clemens, Wang, Zhu, Saber Tehrani, Fanai, Hassoon, & Siegal, *supra* note 152.

186. See Balogh, Miller, & Ball, *ee Policy Roadmap*, *supra* note 160.

187. See *id.* at 107; Newman-Toker et al., *supra* note 15.

188. *But see* Balogh, Miller, & Ball, *supra* note 125, at 49 (“Overuse of diagnostic testing has been partially attributed to clinicians’ fear of missing something important and intolerance of diagnostic uncertainty: ‘I am far more concerned about doing too little than doing too much . . .’”).

189. Dayna Bowen Matthe, *Toward A Structural Theory of Implicit Racial and Ethnic Bias in Health Care*, 25 HEALTH MATRIX 61, 62 (2015).

Research has revealed that public healthcare providers tend to “hold negative explicit and implicit biases against many marginalized groups of people, including racial and ethnic populations, disabled populations, and gender and sexual minorities, among others.”<sup>190</sup> Unfortunately, these attitudes and beliefs can negatively affect the healthcare for people of color racialized and exacerbate existing health disparities.<sup>191</sup> Additionally, the attitudes of providers have been shown to influence healthcare access among PWD.<sup>192</sup>

Further, these biases are particularly harmful in the medical diagnostic process, where implicit assumptions can expose some patients to lower-quality or substandard care. Healthcare professionals, like all people, carry implicit bias, who make medical decisions about their patients’ care. Though unconscious, these biases can have significant and powerful effects on the health and care of the patient. Extensive research reveals the influence and detrimental effects of implicit bias within our healthcare system, including on medical decision-making and the diagnostic process.<sup>193</sup>

Diagnostic errors are often the result of clinician biases and failed heuristics (mental shortcuts).<sup>194</sup> One of the most common cognitive errors is premature closure of the diagnostic process, which occurs when a clinician settles on a diagnosis too early without adequately considering alternative diagnoses, potentially arriving at the wrong one.<sup>195</sup> Premature closure of this process may result in a failure to establish the correct diagnosis.<sup>196</sup> Bias and assumptions made early in the diagnostic process can cause physicians to overlook or miss key information needed for determining a *correct* diagnosis.<sup>197</sup>

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190. Monica B. Vela, Amarachi I. Erondu, Nichole A. Smith, Monica E. Peek, James N. Woodruff, & Marshall H. Chin, *Eliminating Explicit and Implicit Biases in Health Care: Evidence and Research Needs*, 43 ANN. REV PUB. HEALTH 477, 478 (2022).

191. David R. Williams & Ronald Wyatt, *Racial Bias in Health Care and Health: Challenges and Opportunities*, 314 JAMA 555 (2015); William J. Hall, Mimi V. Chapman, Kent M. Lee, Yesenia M. Merino, Tainayah W. Thomas, B. Keith Payne, Eugenia Eng, Steven H. Day, & Tamera Coyne-Beasley, *Implicit Racial/Ethnic Bias Among Health Care Professionals and Its Influence on Health Care Outcomes: A Systematic Review*, 105 AM. J. PUB. HEALTH e60, e72 (2015).

192. Nancy Sharby, Jacqueline Martire & Christine Basile, *Decreasing Health Disparities for People with Disabilities Through Improved Communication Strategies and Awareness*, 12 INT'L J. ENV'T RES. PUB. HEALTH 3301 (2015).

193. Dipesh P. Gopal, Ula Chetty, Patrick O’Donnell, Camille Gajria, & Jodie Blackadder-Weinstein, *Implicit bias in healthcare: clinical practice, research and decision making*, 8 FUTURE HEALTHCARE J. 40 (2021).

194. See Caroline Wellberry, *Flaws in Clinical Reasoning: A Common Cause of Diagnostic Error*, 84 AM. FAM. PHYSICIAN 1042 (2011).

195. See Holland M. Kaplan, Jacqueline F. Birnbaum, & Prathit A. Kulkarni, *Pursuit of “Endpoint Diagnoses” as a Cognitive Forcing Strategy to Avoid Premature Diagnostic Closure*, 9 DIAGNOSIS 421 (2022).

196. *Id.*

197. Some common cognitive biases that result in the exclusion of key diagnostic information include anchoring bias, or “[f]ocusing on initial information in a patient’s presentation result[ing] in an early diagnosis [] despite pertinent information available later during information gathering,” availability bias, or encountering a disease less frequently, which “decrease[s] the chance of making that diagnosis,” along with premature closure, as described above. For more examples, see Gopal, Chetty, O’Donnell, Gajria & Blackadder-Weinstein, *supra* note 196, at 44.

### DANGERS OF MISDIAGNOSIS

Delays in diagnosis can create self-doubt, mental distress, social isolation, family strain, and physical discomfort.<sup>198</sup> Sometimes, delays in diagnoses can be fatal.<sup>199</sup>

While misdiagnosis can happen to any patient, research reflects that the gender of the patient influences when and whether a patient is diagnosed correctly.<sup>200</sup> Women are misdiagnosed at higher rates than men.<sup>201</sup> Misdiagnosis can range from frustrating to even fatal consequences. Given the ties of misdiagnosis to gender, this can spell disaster for women in the U.S. healthcare system.

## IV. THE LAW

This section examines the treatment of women with disabilities, particularly those with non-apparent disabilities. To help illustrate the unique experience of these women, this work considers how this population is treated within the U.S. legal system, more broadly within society, and within the U.S. healthcare system. The framework of intersectionality is explored within the context of healthcare, as understanding the intersecting and competing identities of female patients with disabilities provides context as to the experiences and needs of this population. This context is critical to understanding how we can better address health disparities among women with disabilities and reduce exposure to diagnostic errors.

### A. INTERSECTIONALITY

This paper uses the framework of intersectionality to explain the unique and specific harm suffered by women with disabilities (particularly those with *non-apparent* disabilities). The term intersectionality was coined by Columbia Law Professor Kimberlé Crenshaw in her 1989 article, *Demarginalizing the Intersection of Race and Sex*. Crenshaw uses the term intersectionality as a mechanism to understand the ways that multiple forms of marginalization may compound.<sup>202</sup> This, in turn, creates obstacles and challenges for specific communities that are not understood within conventional ways of thinking.<sup>203</sup> The concept of intersectionality has roots in Black feminist theory and was used to refer to the double-discrimination of racism and sexism faced by Black women.<sup>204</sup> To illustrate this, Crenshaw used legal cases where women had to choose between bringing a claim of racism or sexism.<sup>205</sup> These women were barred from explaining that

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198. See Newman-Toker, Nassery, Schaffer, Yu-Moe, Clemens, Wang, Zhu, Saber Tehrani, Fanai, Hassoon, & Siegal, *supra* note 123 at 9.

199. *Id.*

200. Cecilia Plaza, *Miss Diagnosis: Gendered Injustice in Medical Malpractice Law*, 39 A. J. GENDER & L. 91-92 (2020).

201. *Id.* at 92.

202. Kimberle Crenshaw, *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics*, 1989 U. CHI. L.F. 139, 140 (1989).

203. *Id.*

204. *Id.* at 149.

205. *Id.* at 141.

they had been discriminated against due to the combined effects of race and sex.<sup>206</sup>

Since Crenshaw introduced this term, intersectionality has been widely used within the research space, in the law, and in political and popular discourse. This framework of recognizing that multiple aspects of one's identity can influence exposure to, frequency, and the nature of discrimination is relevant to this current piece. Intersectionality is an analytical tool that can help us to better understand the effects of discrimination and disadvantage experienced by individuals who have multiple categories of social identity that interact with each other.<sup>207</sup> Intersectionality as a concept allows us to move beyond traditional frameworks that separate social problems into distinct challenges facing each group. Intersectionality starts with the premise that people have multiple identities. Individuals can be members and a part of more than one "group."<sup>208</sup> At times, these identities may overlap or interact with one another. An individual may also simultaneously experience oppression and privilege.<sup>209</sup>

Intersectionality is a helpful framework for considering how to better protect women with disabilities. Another aspect is looking towards key disability frameworks. The following section describes the disability models—the medical model and the social model. The social model represents the ideal; it is a model that both helps and empowers people with disabilities. Despite the potential of the social model, society continues to rely on the medical model. The medical model is also the one entrenched in our laws that fails to protect people with disabilities and perpetuates the disability binary of disabled or not.

## B. DISABILITY FRAMEWORK (MODELS OF DISABILITY)

In thinking about disability, healthcare, and the law, it is key to discuss two disability models: the medical model of disability and the social model of disability. The medical model of disability is significant, as it heavily influences current laws and how PWD are treated under the law. As the following section will discuss, the medical model of disability allows for an othering effect and various loopholes that prevent PWD from being protected under the laws.

Disability models influence the framework used to construct laws and policies. The medical model is cemented in the medical field, as doctors determine whether an individual has an impairment<sup>210</sup> or loss of function.<sup>211</sup> This approach

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206. *Id.*

207. SCOTTISH GOV'T, USING INTERSECTIONALITY TO UNDERSTAND STRUCTURAL INEQUALITY IN SCOTLAND: EVIDENCE SYNTHESIS (2022).

208. *Center for Intersectionality and Social Policy Studies*, COLUM. L. SCH., <https://perma.cc/XH8T-NXJ3> (last visited Sept. 21, 2025).

209. *Id.*

210. Impairment and illness are used interchangeably.

211. See DEBORAH A. STONE, THE DISABLED STATE 108 (1984) for an exposition of the medical model; see also SAMUEL R. BAGENSTOS, LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT 37 (2009) for an explanation of the tensions between the medical and social model, including how the medical model enables access to accommodations through civil rights litigation.

has not stayed confined to the medical profession—where it belongs. Instead, the medical model has seeped into the thoughts, perceptions, and behaviors of physicians along with the perspectives held in broader society. This, in turn, results in the view that people with disabilities are impaired.

Under the medical model structure of our laws—again we see this binary where—an individual is either disabled or not. The medical model considers disability as a “personal tragedy, which suggests that a disability is some terrible chance event that occurs at random to unfortunate individuals.”<sup>212</sup> “Accordingly, this model fixates the ‘problem’ within the individual while simultaneously absolving society from further consideration.”<sup>213</sup> “This model also views the individual with pity, as defective, or as having an impairment that must be eliminated, treated, or cured.”<sup>214</sup> Society, in agreeing to assign medical meaning to *disability*, keeps PWD at the fringes of society resulting in their marginalization.<sup>215</sup>

Alternatively, the social model of disability empowers people with disabilities by recognizing that disability is socially constructed.<sup>216</sup> Unlike the medical model, the social model proposes that society disables individuals.<sup>217</sup> Social structures create disabilities:<sup>218</sup> there is nothing deficient nor wrong with individuals with disabilities but, rather, diverse ways of existing in the world.<sup>219</sup> Michael Oliver developed the social theory of disability in *The Politics of Disablement*, in which he brings that consciousness – that social structures create disabilities –, already present in the disability community, to academia.<sup>220</sup> Again, this consciousness reflects the understanding that society creates disability.

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212. See Guevara, *supra* note 119, at 277-79 (explaining the medical model’s failings as a framework for disability antidiscrimination law). The root of the problem is that the medical model perpetuates “othering,” affecting us all, but further impacting People of Color. *Id.* at 270. An illness is separate from the disability. *Id.* at 276.

213. *Id.* at 278.

214. *Id.*; STONE, *supra* note 194, at 107–17 (discussing the medical evaluation of impairment); DAN GOODLEY, DIS/ABILITY STUDIES: THEORIZING DISABLISM AND ABLEISM 16 (2014) (“Disability is established in the *World Report* as a problematic dynamic phenomenon requiring the immediate response of nations states, their governments and their citizens.”).

215. See SIMI LINTON, CLAIMING DISABILITY: KNOWLEDGE AND IDENTITY 11–12 (1998) (describing the difference between definitions of “disability”: its medical definition, which has a negative connotation, and its definition as a social/political category, which relates to the identity of “a group bound by common social and political experience”).

216. TOM SHAKESPEARE, DISABILITY RIGHTS AND WRONGS REVISITED 106 (2d ed., 2014) (“What divides disabled from non-disabled people, in [the social model] formulation, is the imposition of social oppression and social exclusion.”).

217. Arlene S. Kanter, *The Law: What’s Disability Studies Got to Do with It or an Introduction to Disability Legal Studies*, 42 COLUM. HUM. RTS. L. REV. 403, 408-409 (2011).

218. *Id.*; Anne Louise Chappell, *Still Out in the Cold: People with Learning Difficulties and the Social Model of Disability*, in THE DISABILITY READER: SOCIAL SCIENCE PERSPECTIVES 211, 214–19 (Tom Shakespeare ed., 1998).

219. See, e.g., Tom Shakespeare, *Disability, Identity, and Difference*, in EXPLORING THE DIVIDE: ILLNESS AND DISABILITY 94, 94–113 (Colin Barnes & Geoff Mercer eds., 1996).

220. See generally MICHAEL OLIVER, THE POLITICS OF DISABLEMENT (1990).

Currently, laws and policies are based on the medical model of disability,<sup>221</sup> which is evident because they tailor assistance and solutions to fit the ableist world rather than normalizing human variation.<sup>222</sup> For the law to apply, a person is either disabled or not disabled, without regard for fluctuating symptoms in disabilities that may render a person disabled one day and not disabled the next. This creates a legal vulnerability not easily remedied through legal means because the issue begins with the framing of disability itself.

The medical model serves as the basis for the current disability anti-discrimination law. Under these laws, disability refers to the existence of physical or cognitive impairments within the individual.<sup>223</sup> These impairments are considered abnormal or undesirable.<sup>224</sup> The medical model helps to raise the question of what or who is *normal*. The concept of normalcy shifts depending on the person. Disabled people are not the problem; the current construction of normalcy presents PWD as the problem. Historically, disability was viewed as something to fix, and thus, there is little willingness to tolerate or accommodate PWD.<sup>225</sup>

The social model on the other hand realizes that disability is socially constructed—how people are seen and experience the world is based on current social norms. The social model maximizes an individual's potential because it challenges the view of normalcy. This, in turn, forces an individual to examine any subconscious bias and assumptions about any given disability. This examination provides the opportunity for individuals to embrace human variation.<sup>226</sup> In accepting this variation, attitudes toward and the treatment of people with disabilities would change.

OUUniversal design challenges the binary of able and disabled. One practical approach that reflects the social model and disrupts this binary is universal design. For instance, consider the universality of having stairs in almost every building – then imagine changing all the staircases to elevators. Architecture and universal design challenge our way of thinking and movement in public space to consider human variation and how to design for everyone. Universal design efforts acknowledge that society disables and questions social norms. This is an example of how the principles in the social model of disability can be incorporated into the larger society.

Furthermore, living under the social model of disability means current laws relying on the ability-disability binary would not exist. Society would have

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221. See generally GUEVARA, *supra*, note 126.

222. See LINTON, *supra*, note 205; Kanter, *supra*, note 207.

223. Licia Carlson, *Rethinking Normalcy, Normalization, and Cognitive Disability*, in SCIENCE AND OTHER CULTURES 154 (1<sup>st</sup> ed. 2003).

224. *Id.*

225. Abram Anders, *Foucault and “the Right to Life”: From Technologies of Normalization to Societies of Control*, 33 DISABILITY STUDS.Q. (2013).

226. See Jerome E. Bickenbach, Somnath Chatterjia, E.M. Badley & T.B. Üstün, *Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps*, 48 SOC. SCI. & MED. 1173, 1173–84 (1999).

normalized human variation and thus provided the necessary adjustments for all individuals to maximize their potential, ultimately prioritizing human dignity. Using this social model of disability – such as through universal design – prompts an individual to think inclusively about people with disabilities instead of constantly viewing them as afterthought. The goal of the medical field is to treat or eliminate illness.<sup>227</sup> If prevention of the illness is not possible, then the next step is to attempt to cure the illness.<sup>228</sup> Finally, if curing fails, the goal is to make the person *appear* as healthy as possible. Since human variation has not yet been accepted, the United States continues to operate under the medical model. The focus on the appearance of normalcy is key—for it calls into question both what is normal and the distinctions that must be made between apparent and non-apparent disabilities. Essentially, relying on the medical model of disability further perpetuates the othering through stigma.<sup>229</sup>

The following section details solutions to address some of the challenges faced by women with disabilities in terms of their health, treatment, and outcomes, alongside the legal pitfalls that fail to protect them.

## V. RECOMMENDATIONS

The subsequent recommendations focus on three key areas: changing ideology on PWD; emphasizing the patient as an active participant in their care; and improving communication with female patients with disabilities. Changing ideology and shifting societal perspectives are necessary for progress. Realizing actual change will require society to move away from the medical model of disability. Though this is not an easy task, it is a necessary one. PWD are consistently overlooked, cast aside, and left outside of broader society. Shifting our focus on how we perceive PWD will allow us to better address their needs and align the law in such a way that it responds to the direct harms that these individuals are facing.

Next is to consider how to better protect women with disabilities in the U.S. healthcare system. As this article discussed, this is a major problem that is costly, not only financially, but also in terms of patient safety, reducing harms, and the overall human and societal cost. All patients—but especially women with disabilities—need to be made into active participants in their own care. This article highlighted the long history of female hysteria and the ways that women were not only left out of their care, but were also overlooked, disbelieved, and othered. These concerns were only compounded if that woman also was experiencing a disability. Further, considering communication networks within healthcare and how we speak to women with disabilities highlights another opportunity to create safer systems and better protect this vulnerable population.

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227. See generally TANYA TITCHKOSKY & ROD MICHALKO, *RETHINKING NORMALCY: A DISABILITY STUDIES READER* (2009).

228. *Id.*

229. See GOFFMAN, *supra* note 112.

### A. CHANGING THE IDEOLOGY ON PWD

*“Disability is not the measles.”<sup>230</sup>*

Regarding health, it is vital to move away from a stagnant perspective of normal or what constitutes an illness. The idea of normal leaves no room for human variation. Comparisons between women with disabilities and other women create an ideological framework that defines disability as abnormal and, within health, equates disability with illness. Women with disabilities have distinct healthcare needs, but this does not make them abnormal<sup>231</sup>—nor should disability be equated with illness. Physical bodies that are marked as disabled depart from what society conceptualizes as the norm.<sup>232</sup> How women with disabilities are treated in the healthcare system is a reflection of how implicit and explicit biases can interfere with an individual’s different needs. To help better address the needs of this population, healthcare must shift focus.<sup>233</sup> Instead of emphasizing the prevention of disabling conditions—which is not always possible—the focus should shift to viewing PWD “as a substantial minority population that experiences health disparities.”<sup>234</sup> To help make this change in how healthcare perceives PWD, the U.S. healthcare system should focus on clearly identifying existing health disparities for this population,<sup>235</sup> and in addition, educate healthcare systems and providers about the disability models that can assist in helping them reframe how they view non-apparent disabilities. Being aware would at least cause a healthcare professional to pause before being dismissive and examine their behavior.

### B. PATIENT AS AN ACTIVE PARTICIPANT

Research has advocated for a patient-centered approach to healthcare.<sup>236</sup> Patient engagement recognizes that patients have an important role to play in their healthcare. This can include reading, understanding, and acting on health information alongside the doctor to make a decision about care.<sup>237</sup> Engaging patients and their families is a growing trend and, in some cases, an expectation.<sup>238</sup> Despite this movement toward directly engaging the patient and involving them in their care, more can be done to involve women with disabilities in

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231. Amanda Reichard, Kassandra S. Stolzle Hocker, & Elizabeth A. Andrews, *Health Disparities Among Adults with Physical Disabilities or Cognitive Limitations Compared to Individuals with no Disabilities in the United States*, 4 DISABILITY HEALTH J. 59(2011).

232. See Rioux & Daly, *supra* note 211.

233. See Reichard et al., *supra* note 212 at 59.

234. *Id.*

235. *Id.*

236. See Bertakis & Azari, *supra* note 1 at 46.

237. Angela Coulter, *Patient Engagement—What Works?*, 35 J. AMBULATORY CARE MGMT. 80 (2012).

238. Kinga Pozniak, Francine Buchanan, Andrea Cross, Jennifer Crowson, Barb Galuppi, Danijela Grahovac, Jan Willem Gorter, Oksana Hlyva, Marjolijn Ketelaar, Olaf Kraus de Camargo, Manda Krpan Mesic, Rachel Martens, Dayle McCauley, Linda Nguyen, Robert J. Palisano, Michelle Phoenix, Connie Putterman, Peter Rosenbaum, Jennifer Sprung, Sonya Strohm, Rachel Teplicky, Donna

their health and overall care. Evidence supports the perspective “that patients ought to be offered information about treatment options and likely outcomes and encouraged to participate in decisions about which option is most appropriate for them.”<sup>239</sup> The root idea behind patient engagement is that the decisions and actions of health professionals only constitute one part of the healthcare process.<sup>240</sup>

Ideally, patients, their families, and even the community would play an equal, if not a larger role, in healthcare.<sup>241</sup> This creates a space where patients, their families, and the community can become a co-producer of health and better care.<sup>242</sup> The active role of patients in their care needs to be recognized and encouraged.<sup>243</sup> Though often overlooked, patients play an instrumental role in their health.<sup>244</sup> First, patients help healthcare professionals reach an accurate diagnosis.<sup>245</sup> Second, patients can work with their provider to determine an appropriate treatment regime.<sup>246</sup> Third, patients should exercise their right to choose an experienced and safe provider.<sup>247</sup> What is safe may vary from patient to patient and according to their needs.<sup>248</sup> Fourth, patients should feel comfortable with their treatment plan and ensure treatment is “appropriately administered, monitored, and adhered to.”<sup>249</sup>

Patients are frequently left out of the conversation in their health and how to address harm they may experience.<sup>250</sup> Instead, patients are seen as passive victims of errors and safety failures.<sup>251</sup> Despite this assumption, there is considerable latitude for patients to take an active role in ensuring their care is effective and appropriate, and to protect their own safety.<sup>252</sup> This is not to place an additional burden on patients who are sick or vulnerable but to allow them the space to be active participants in their care.<sup>253</sup> Patients should not be seen as passive recipients of medical care. Instead, an unrecognized opportunity exists for them to play a much more active role where their needs are recognized.<sup>254</sup>

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Thomson & Marilyn Wright, *Building a Culture of Engagement at a Research Centre for Childhood Disability*, 7 RES. INVOLV. ENGAG. 1, 1 (2021).

239. Charles A. Vincent & Angela Coulter, *Patient Safety: What About the Patient?*, 11 QUALITY & SAFETY HEALTH CARE 76, 80 (2002).

240. See Coulter, *supra* note 220 at 80.

241. *Id.*

242. *Id.*

243. *Id.*

244. *Id.*

245. *Id.*

246. *Id.*

247. *Id.*

248. *Id.*

249. *Id.*

250. *Id.*

251. *Id.*

252. *Id.*

253. *Id.*

254. *Id.*

The steps outlined above should be done for all patients, as this is needed to create safer systems overall. As this paper has demonstrated, women (and women with disabilities) are more likely to be ignored and exposed to error within the healthcare system. More efforts need to be put in place to help engage women with disabilities as active participants in their care, given their vulnerability, the perpetuation of female hysteria, and the persisting effects of stigma and othering.

### C. TARGETING COMMUNICATION WITH PATIENTS

Communication in healthcare is critical. The ability to spread and share information seamlessly across departments, labs, specialists, and even across different hospitals can make all the difference in patient care. Communication flow is not only important for sharing information, but also for helping prevent or reduce the occurrence of errors. Communication breakdowns function as a large source behind the occurrence of error. A growing body of research has sought to understand the root causes of such errors and to identify strategies to prevent or eliminate the circumstances that allow such an error to occur.<sup>255</sup> Developing solutions to target the root issues of communication breakdowns could help reduce missed and delayed diagnoses in care.<sup>256</sup>

Alongside considerations of the flow in communication, how and what is communicated to patients is incredibly important. The failure to communicate in healthcare is detrimental to the health of women.<sup>257</sup> Women with disabilities—particularly those that are non-apparent—face unique challenges in the U.S. healthcare system.<sup>258</sup> These women are ignored, not taken seriously, and their concerns are not taken into account when it comes to their care.<sup>259</sup> The response of the U.S. healthcare system is abysmal and further contributes to disparities in care and overall health.<sup>260</sup> This failure to listen is a missed opportunity to learn from the patient and to help improve the diagnostic process.<sup>261</sup> Further, it is a missed opportunity to improve the understanding of the patient, which can lead to better adherence to treatment and produce better overall health outcomes.<sup>262</sup>

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255. David E. Newman-Toker, Najlla Nassery, Adam C Schaffer, Chihwen Winnie Yu-Moe, Gwendolyn D Clemens, Zheyu Wang, Yuxin Zhu, Ali S Saber Tehrani, Mehdi Fanai, Ahmed Hassoon, and Dana Siegal, *Burden of Serious Harms from Diagnostic Error in the USA*, 33 BMJ QUALITY & SAFETY 109 (2024); Martin A. Makary & Michael Daniel, *Medical error—the third leading cause of death in the US* 353 BRIT. MED. J. 236, 236-37 (2016); Phoebe Jean-Pierre, *Why Medical Error is Killing You (and Everyone Else)*, 57 U. MICH. J.L. REFORM 481 (2024).

256. Daniel R. Murphy et al., *Communication Breakdowns and Diagnostic Errors: A Radiology Perspective*, 1 DIAGNOSIS 253 (2014).

257. See Janine W.Y. Kee, Hwee Sing Khoo, Issac Lim, and Mervyn Y.H. Koh, *Communication Skills in Patient-Doctor Interactions; Learning from Patient Complaints*, 4 HEALTH PROF. EDUC. 97, 97 (2018); George Alvarez & Enrico Coiera, *Interdisciplinary Communication: An Uncharted Source of Medical Error?*, 21 J. CRITICAL CARE 236, 236 (2006).

258. Lisa I. Iezzoni, *Make No Assumptions: Communication Between Persons with Disabilities and Clinicians*, 18 ASSIST. TECH. 212, 212 (2006).

259. See *id.*; Smeltzer, Sharts-Hopko, Ott, Zimmerman, & Duffin., *supra* note 11.

260. See Kee, Khoo, Lim & Koh, *supra* note 237.

261. See Vincent & Coulter, *supra* note 220.

262. *Id.*

“Female hysteria” as a historical phenomenon has resulted in women being overlooked and dismissed when they seek genuine care. By brushing aside women’s concerns and symptoms, the consequences of this dismissive approach are profound. Women’s health needs, emotional well-being, and social realities are ignored or minimized, resulting in inadequate treatment, neglect, and marginalization. By framing women’s experiences as symptoms of hysteria—society and the medical establishment effectively marginalized women’s authentic struggles and reinforced gender stereotypes that saw women as inherently emotionally unstable or incapable of rational decision-making. Unfortunately, these same perspectives translate into how we communicate with and treat women in healthcare, whether they have a disability or not. Improving communication with women with disabilities is critical to improving their health outcomes and reducing their exposure to error. Fostering open, transparent communication can help build safer systems overall, reduce the number of errors and malpractice rates, and lower the financial and human costs that accumulate and impact society.

#### CONCLUSION

Women with disabilities remain uniquely vulnerable within the U.S. healthcare system; caught at the intersection of gender bias and systemic legal inadequacies. Explicit and implicit biases among healthcare professionals create an *othering* effect that leads to diagnostic errors. This cycle perpetuates the ongoing health disparities plaguing women with disabilities, further entrenching their marginalization within healthcare settings.

While women, in general, are more readily dismissed by healthcare providers compared to men, the presence of a non-apparent disability adds yet another layer of skepticism and systemic barriers. Women with disabilities, particularly those whose disabilities are non-apparent, face unique challenges in not being believed, understood, or treated effectively. Unfortunately, the legal system offers little recourse. Disability anti-discrimination laws fall short, as they are rooted in the outdated medical model of disability. This model fails to protect and consider the needs of women with non-apparent disabilities.

Without proper protections, these women are left to their own devices in trying to navigate the medical and legal systems that simultaneously overlook and devalue their humanity. The consequence is a compounding effect: diagnostic errors, pervasive dismissal, and systemic neglect, all of which perpetuate their vulnerability and health disparities.

This article bridges these critical issues by examining the intersection of gender, disability, and diagnostic error. It underscores the urgent need for systemic reforms in healthcare and legal frameworks particularly for women with non-apparent disabilities. Only by addressing these persistent biases and moving to the social model of disability can the healthcare and legal systems begin to repair the harm and neglect that women with disabilities currently face in their health outcomes and treatment.