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Cultural Collisions and the Limits of the Affordable Care Act

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CULTURAL COLLISIONS AND THE LIMITS OF THE AFFORDABLE CARE ACT

JASMINE E. HARRIS*

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INTRODUCTION

National Federation of Independent Business v. Sebelius (“*NFIB*”) settled the central constitutional questions impeding the rollout of the Patient Protection and Affordable Care Act (“Affordable Care Act” or “ACA”): whether the federal government’s “individual mandate” to purchase or hold health insurance and the federal government’s authority to retract existing federal dollars if states fail to expand Medicaid eligibility violate the Constitution.¹ However, a number of residual questions persist in its wake. While most of the focus this year has been on related constitutional issues—such as religious exemptions from offering contraceptive coverage to employees²—*NFIB* also clears the path for a discussion of the merits of the ACA’s policy goals and the extent to which the ACA succeeds on its own terms.

Undeniably, the ACA will narrow the qualitative divide between the scope of coverage in private and public insurance markets. The ACA is the first *comprehensive* federal health care legislation to reorganize financing and delivery of health care based on three guiding principles: quality, access, and equitable outcomes. For example, the ACA expands public health insurance by offering financial incentives³ for states to expand

1. Nat’l Fed’n of Indep. Bus. v. Sebelius, 132 S. Ct. 2566 (2012).

2. See *Conestoga Wood Specialties Corp. v. Sec’y of U.S. Dep’t. of Health & Human Servs.*, 724 F.3d 377 (3d Cir. 2013), *cert. granted*, ___ U.S.L.W. ___ (U.S. Nov. 26, 2013) (No. 13-354); *Hobby Lobby Stores, Inc. v. Sebelius*, 723 F.3d 1114 (10th Cir. 2013), *cert. granted*, ___ U.S.L.W. ___ (U.S. Nov. 26, 2013) (No. 13-356). See generally Ethan Bronner, *Religious Groups and Employers Battle Conception Mandate*, N.Y. TIMES (Jan. 26, 2012), <http://www.nytimes.com/2013/01/27/health/religious-groups-and-employers-battle-contraception-mandate.html>.

3. See, e.g., Patient Protection and Affordable Care Act, 42 U.S.C. § 18001

Medicaid eligibility to residents with incomes up to 138%⁴ of the federal poverty level, and, in the private market, offers federal subsidies to individuals with incomes up to 400% of the federal poverty level to purchase private insurance through newly established insurance exchanges. Even discounting the handful of states opting out of Medicaid expansion,⁵ millions of newly insured people will enter the formal health care system in 2014—a tremendous achievement.⁶

Post-*NFIB*, discussions of the ACA tend to focus on these policy outcomes—most visibly on access, and on the ACA, more generally—as an unmistakably good thing. However, meaningful access to quality health care is not a simple question of coverage affordability as a legal or policy matter. Insurance may be a gateway to accessing care but if the health delivery system lacks competence and capacity to build sustainable relationships, and recognize and respond to cultural differences in illness perception, health outcomes will not improve.⁷

(2010) [hereinafter ACA], Title II, § 2001 (explaining fiscal incentives to states); *see also infra* Part III.A.1.

4. 133% plus a 5% income disregard. *See* CONG. BUDGET OFFICE, ESTIMATES FOR THE INSURANCE COVERAGE PROVISIONS OF THE AFFORDABLE CARE ACT UPDATED FOR THE RECENT SUPREME COURT DECISION 6-7 (July 2012), *available at* <http://www.cbo.gov/sites/default/files/cbofiles/attachments/43472-07-24-2012-CoverageEstimates.pdf>.

5. Twenty-five states (Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Hawaii, Illinois, Iowa, Kentucky, Maryland, Massachusetts, Michigan, Minnesota, Nevada, New Jersey, New Mexico, New York, North Dakota, Ohio, Oregon, Rhode Island, Vermont, Washington, and West Virginia) and the District of Columbia are participating in Medicaid expansion; two states are seeking to move forward with expansion post-2014 (Indiana and Pennsylvania); and twenty-three states have rejected federal dollars for Medicaid expansion (Alabama, Alaska, Florida, Georgia, Idaho, Indiana, Kansas, Louisiana, Maine, Mississippi, Montana, Nebraska, New Hampshire, North Carolina, Oklahoma, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, Wisconsin, and Wyoming). *See Status of State Action on the Medicaid Expansion Decision, as of December 11, 2013*, KAISER FAMILY FOUND., <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/> (last visited Jan. 10, 2014).

6. Congressional Budget Office estimates predict that the ACA will reduce non-elderly uninsured individuals by 14 million in 2014 and by 29 million or 30 million in the latter part of the coming decade, leaving 30 million non-elderly residents uninsured by the end of the period. CONG. BUDGET OFFICE, ESTIMATES FOR THE INSURANCE COVERAGE PROVISIONS OF THE AFFORDABLE CARE ACT UPDATED FOR THE RECENT SUPREME COURT DECISION (July 2012), *available at* <http://www.cbo.gov/sites/default/files/cbofiles/attachments/43472-07-24-2012-CoverageEstimates.pdf>.

7. *See, e.g.,* Barak D. Richman, *Behavioral Economics and Health Policy: Understanding Medicaid's Failure*, 90 CORNELL L. REV. 705, 709-710 (2005) (“Public debates and legislative efforts have fretted over insurance when instead they should have focused on health.”); *see also* Lorian E. Hardcastle et al., *Improving the*

Perhaps the most egregious examples of inaccessible health care can be found in the mental health arena, where demand is high, providers are in short supply,⁸ and people in need of support services are most often silenced and presumed to lack decision-making capacity on account of their mental and psychosocial disabilities.⁹ Racially and ethnically diverse communities “bear a greater burden from unmet mental health needs [than do whites] and thus experience a greater loss to their overall health and productivity.”¹⁰ They have less access to mental health services than do

Population's Health: The Affordable Care Act and the Importance of Integration, 39 J.L. MED. & ETHICS 317 (2011).

8. In 2010, the Bureau of Labor Statistics reported 156,300 mental health counselors nationally. Sarah Kliff, *Seven Facts About America's Mental Health-Care System*, WASH. POST (Dec. 17, 2012, 1:09 PM), <http://www.washingtonpost.com/blogs/wonkblog/wp/2012/12/17/seven-facts-about-americas-mental-health-care-system>. Access to mental health professionals is worse than for other types of doctors—89.3 million Americans live in federally-designated Mental Health Professional Shortage Areas (HRSA makes the designations by county), compared to 55.3 million Americans living in similarly designated primary-care shortage areas and 44.6 million in dental health shortage area. See HEALTH RES. & SERVS. ADMIN., DESIGNATED MENTAL HEALTH CARE HEALTH PROFESSIONAL SHORTAGE AREAS (2011), available at <http://bhpr.hrsa.gov/shortage/hpsas/updates/09012011mentalhpsas.html>.

9. See, e.g., Robert D. Dinerstein, *Guardianship and Its Alternatives for Adults with Down Syndrome*, in ADULTS WITH DOWN SYNDROME (Siegfried Pueschel ed., 2006) (discussing, in the context of developmental disabilities, the default position of blanket lack of capacity for all decision-making).

10. SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., U.S. DEP'T OF HEALTH & HUMAN SERVS., MENTAL HEALTH: CULTURE, RACE, AND ETHNICITY—A SUPPLEMENT TO MENTAL HEALTH: A REPORT OF THE SURGEON GENERAL 3 (Aug. 2001), available at <http://www.ncbi.nlm.nih.gov/books/NBK44243/pdf/TOC.pdf>; see INST. OF MED., UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE 1 (Brian D. Smedley et al. eds., 2003) [hereinafter INST. OF MED.]; PRESIDENT'S NEW FREEDOM COMM. ON MENTAL HEALTH, ACHIEVING THE PROMISE: TRANSFORMING MENTAL HEALTH CARE IN AMERICA, NAT'L ALLIANCE ON MENTAL ILLNESS (July 22, 2003), available at http://www.nami.org/Template.cfm?Section=New_Freedom_Commission&Template=/ContentManagement/ContentDisplay.cfm&ContentID=28335; AGENCY FOR HEALTHCARE RES. & QUALITY, U.S. DEP'T OF HEALTH & HUMAN SERV., AHRQ PUB. NO. 06-0017, NATIONAL HEALTHCARE DISPARITIES REPORT 2-3 (2005). Scholars have been writing about the two-tiered health care system for more than thirty years. See, e.g., Geraldine Dallek, *Health Care for America's Poor: Separate and Unequal*, 20 CLEARINGHOUSE REV. 361 (1986) (Special Issue); Jonathan Gruber, *The Case for a Two-Tier Health System*, PATHWAYS, 13 (Winter 2009), available at <http://economics.mit.edu/files/6415>; Benjamin J. Krohmal & Ezekiel J. Emanuel, *Tiers Without Tears: The Ethics of a Two-Tier Health Care System*, in OXFORD HANDBOOK (2009), available at <http://www.oxfordhandbooks.com/view/10.1093/oxfordhb/9780199562411.001.0001/oxfordhb-9780199562411-e-008>; John Goodman, *Coming Soon to America: A Two-Tiered, Canadian-Style Health Care System*, FORBES (May 23, 2013), <http://www.forbes.com/sites/johngoodman/>

whites because of restrictive health plans, the absence of providers, and normative differences in beliefs about health and illness. Furthermore, when they do access mental health care, it is more likely poorer in quality.¹¹

The ACA demonstrates the same monochromatic approach that current U.S. health care policy takes to ensuring meaningful access across cultural divides. This Article focuses on the Affordable Care Act and mental health promotion among Latinos as one of the clearest examples of the overly simplistic approach denying meaningful access to racially and ethnically diverse communities. Specifically, this Article demonstrates that the ACA is limited in its ability to improve mental health outcomes among racially and ethnically diverse communities because it does not reach or, at best, narrowly addresses the ways in which health care has been historically defined, delivered, regulated, and experienced in the United States. The cornerstone of mental health care delivery continues to be highly specialized and concentrated among “culturally incompetent”¹² medical doctors, in a paternalistic doctor-patient relationship, and regulated at the state level. Current mental health care institutions assume a set of legitimate diagnostic categories of illness for the receipt of treatment and promotion of health. While the ACA does address some of these barriers, such as eliminating the dominant fee-for-service insurance model, supporting the expansion of the primary care workforce and peripheral cultural competency efforts, it is—on its own terms—insufficient to improve mental health outcomes. The complexities surrounding cultural norms of health and illness, particularly in the mental health arena, demand more heterogeneous models of health care delivery than are currently available or reimbursable under public and private insurance plans.

Consider the following true story to illustrate the limits of the ACA to improve mental health outcomes:

Isabel,¹³ a 35 year-old legal immigrant from Mexico, works as a house cleaner. She lives with her husband, José, a contract construction worker, and their children in a predominantly Latino community in New York City. Neither is fluent in English but both have a basic level of comprehension. For the past six months, José has been unable to find regular work and Isabel has taken on additional cleaning jobs to compensate for the loss of a second household income, sometimes working upwards of 60 hours, six days a week. Isabel has been

2013/05/23/coming-soon-to-america-a-two-tiered-canadian-style-health-care-system.

11. INST. MED., *supra* note 10, at 2.

12. Lisa C. Ikemoto, *Racial Disparities in Health Care and Cultural Competency*, 48 ST. LOUIS U. L.J. 75, 76 (2003) (defining the term cultural competency).

13. All names have been changed for confidentiality purposes.

particularly tired and sad with frequent stomach aches, headaches, fatigue, and vomiting. She also has periods of feeling very anxious sometimes accompanied by sweating and shaking. Isabel is worried but does not know what to do. After consulting with friends, her church Pastor, and a ‘curandera’ (spiritual healer), Isabel concludes that there is nothing serious to worry about and she is just overwhelmed by the changes in her household. She has been told by others (and has come to believe) that she has been experiencing an ‘ataque de nervios’ (episode of extreme nervousness) and needs more rest and time to recover her strength.

Isabel waits for things to change and when they do not and, in fact, her stomach pains worsen, she hesitantly goes to see a primary care physician at a free mobile clinic. Isabel and her husband do not have health insurance and they visit the emergency room as needed. Isabel’s visit to the mobile clinic left much to be desired—for example, a two-hour wait for a fifteen-minute appointment. As Isabel listened to Dr. Smith’s diagnosis and treatment recommendations through his Spanish-speaking medical student intern, Helena, she thought how off-base they seemed. Isabel had come to the medical clinic for her stomach aches and ‘nervios’ and now they were trying to tell her she was ‘depressed’ and give her medication. She asked Helena to reiterate to Dr. Smith that it was just ‘nervios’ and she had already talked to others about it, including a curandera, who said she is fine. Helena relayed the information that Isabel recognized as a literal translation of her words. Dr. Smith paused, looked skeptically at Helena, and continued with his treatment plan. Isabel received Dr. Smith’s dismissal as a clear message of his unwillingness to understand or listen to her. Isabel threw away the prescriptions and the list of referrals for psychiatric care because she did not want her husband, friends, or family to find it and think that she was ‘una loca’ (a crazy woman).

Isabel’s encounter with the formal health care system reflects an increasingly common reality among racially and linguistically diverse communities in the United States, who disproportionately live below the poverty line, most often lack health insurance, and receive acute but not regular preventive care.¹⁴ The growth of culturally and linguistically diverse communities is unprecedented and will likely continue.¹⁵

14. Census data shows that 30% of people who speak a language other than English in the home (about 18.3 million) live below the poverty line, and 38% of those who speak a language other than English in the home lack health insurance. CAMILLE RYAN, U.S. DEP’T OF COMMERCE, LANGUAGE USE IN THE UNITED STATES: 2011, at 9 (2013), available at <http://www.census.gov/prod/2013pubs/acs-22.pdf>.

15. The U.S. Census Bureau describes this trend as America’s shift to a “plurality nation” where no one ethnic or racial group defines the majority. Michael Cooper, *Census Officials, Citing Increasing Diversity, Say U.S. Will be a ‘Plurality Nation,’* N.Y. TIMES (Dec. 12, 2012), <http://www.nytimes.com/2012/12/13/us/us-will-have-no->

Approximately 61 million people¹⁶ in the United States (or twenty-one percent of the population) currently speak a language other than English at home; twenty-two percent of the U.S. population self-reports little or no knowledge of the English language.¹⁷ The need for improved language access is well-accepted even if not well-enforced;¹⁸ but, it is the more nuanced concept of cultural competence—often mistakenly equated with linguistic competence—that demands greater attention. For example, 13 million people in the United States are foreign born and approximately one in three people identifies as Hispanic/Latino, Black, or Asian.¹⁹ While language is an integral component of culture,²⁰ culture is much broader and generally reflects a common set of values or beliefs that are socially constructed in similar settings. Cultural norms include particular help-seeking behaviors, views of autonomy and control, and problem-solving processes, as well as conceptions of pain—all central to health promotion.²¹

With increased acculturation and greater knowledge and use of the English language over native languages, later generations may retain cultural norms without language fluency.²² Interestingly, studies show that increased acculturation correlates with poorer health status, particularly mental health, among linguistically and culturally diverse communities. This phenomenon is most often attributed to the accumulation of negative

ethnic-majority-census-finds.html.

16. Ages 5 and up.

17. RYAN, *supra* note 14, at 3.

18. See, e.g., Joel Teitelbaum et al., *Translating Rights into Access: Language Access and the Affordable Care Act*, 38 AM. J.L. & MED. 348, 364 (2012) (providing useful background regarding language access movement and related legislation and jurisprudential development and emphasizing need for enforcement of existing laws and suggestion of new legislation to further language access rights).

19. RYAN, *supra* note 14, at 9.

20. See Alina M. Perez & Kathy L. Cerminara, *La Caja Pandora: Improving Access to Hospice Care Among Hispanic and African Patients*, 10 HOUS. J. HEALTH L. & POL'Y 255, 265-66 (2010).

21. See, e.g., Lee Pachter, *Culture and Clinical Care: Folk Illness Beliefs and Behaviors and Their Implications for Health Care Delivery*, 271 JAMA 690 (1994) (exploring the role of culture in diagnosis and treatment within the doctor-patient relationship).

22. For example, among Latinos, “although certain aspects of familism—a sense of obligation and the power of the family as a behavioral referent—change as an individual becomes more acculturated, others (e.g., support received and expected from relatives) remain important to highly acculturated Latinos as well as to the less acculturated.” Marielena Lara et al., *Acculturation and Latino Health in the United States: A Review of the Literature and its Sociopolitical Context*, 26 ANN. REV. PUB. HEALTH 367, 371 (2005), available at http://www.rand.org/content/dam/rand/pubs/reprints/2005/RAND_RP1177.pdf.

interactions with U.S. institutions and the loss of social and familial networks.²³ Social and economic isolation increases over time and can lead to greater psychosocial stressors and increased substance use.²⁴

The ACA's focus on access to insurance and greater parity in mental health coverage will not likely improve Isabel's health, or the millions like her, because it does not address at least three complicating factors: (1) cultural differences in mental health norms of diagnosis and treatment; (2) the lack of patient-centered care Isabel receives and the suppression of her voice in the diagnostic process; and (3) the integration or collaboration among existing community supports that may currently compete with formal health care services. Using Isabel's story as a lens, this Article shows how—and why—the ACA is deficient in this regard, and suggests lessons for reforms going forward.

This critique is less an indictment of the ACA itself than of how we in the United States discuss health care delivery and mental health care in particular. For health law²⁵ to successfully bridge the cultural divide and improve health outcomes, it must both (1) incorporate the lessons of critical legal theorists and disability scholars, contextualize health care delivery, and respond to diverse norms of health and illness; and (2) formally integrate and value collectivist decision-making and knowledge sharing models in health care delivery by reimagining the doctor-patient relationship. This effort requires a significant normative shift recognizing the social constructions inherent in health laws that have historically marginalized linguistically and ethnically diverse communities, particularly those with mental and psychosocial disabilities. Moreover, the foundational principles of health law—premised on the identification and treatment of physical or mental impairments—often collide with the guiding tenets of disability law, which view such impairments as disabling only or mainly as a consequence of social organization.²⁶

23. DVD: *Unnatural Causes: Becoming an American* (Public Broadcasting Service 2008), available at http://www.unnaturalcauses.org/assets/uploads/file/UC_Transcript_3.pdf.

24. WORLD HEALTH ORG., *SOCIAL DETERMINANTS OF HEALTH: THE SOLID FACTS* 16-17 (Richard Wilkinson and Michael Marmot eds., 2d ed. 2003), available at http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf.

25. I refer to health law herein as legislation and doctrine related to receipt of health care benefits including both public and private health insurance as well as social welfare benefits. The ACA self-identifies with the health law frame yet many of its provisions incorporate civil rights concepts such as equality of access.

26. Despite this tension, disability scholars recognize the importance of health law in obtaining the necessary support to advance community inclusion. See, e.g., Mary Crossley, *SYMPOSIUM: THE AMERICANS WITH DISABILITIES ACT: A TEN-YEAR RETROSPECTIVE: Becoming Visible: The ADA's Impact on Health Care for Persons*

This Article shifts the conversation about meaningful access to mental health care from a narrow focus on the individual's deficits and bio-medical modifications to broader limitations in societal perceptions of health, illness, and what constitutes "care." To unpack this argument, this Article proceeds as follows. Part I frames disparities in mental health care (illustrated by Isabel's experience) as a denial of "meaningful access." Given the limits of federal constitutional and statutory law to provide a justiciable remedy for Isabel, I look to civil rights jurisprudence more broadly regarding access to public benefits. I highlight the unanimous position adopted by all three branches of government that mistakenly equates language access with cultural competency. Therein, I suggest that Isabel's relief must instead come from legal and policy reform at the state level. A discussion of U.S. norms of mental health, illness, and care provides additional support for viewing Isabel's issues as complex and demonstrates why mental health care institutions cannot (as currently structured) provide relief. Part I concludes with a closer examination of mental health care disparities among Latinos and why this phenomenon has broader applicability to other racially and ethnically diverse communities.

In Part II, I turn to the ACA itself, the construction of its mental health agenda, and its central provisions purportedly in service of those goals. I begin by classifying the ACA's mental health goals into three descriptive groups: (1) access issues and entry into the health care system, (2) the process of health care delivery, and (3) improved health outcomes. Therein, I describe the primary goal for each group of reforms and present the relevant provisions in the ACA scheduled to advance those goals.

Part III returns to the opening narrative of Isabel as a lens to process the practical impact of the ACA's reforms outlined in Part II. This section explains the limitations and dangers of our "one size fits all" health care delivery model through Isabel's encounter with Dr. Smith. I conclude this section by introducing key lessons for reconceptualizing health care delivery rooted in three principles: patient-centered care, expanded expertise, and collective decision-making. These principles should guide state implementation of the ACA in order to promote sustainable, long-term improvements in mental health status among culturally and linguistically diverse communities.

with Disabilities, 52 ALA. L. REV. 51, 53 (2000) ("[B]ecause many persons with disabilities have ongoing and sometimes extensive health care needs as a result of their disabilities, legal protection against discrimination in accessing health care services can be of critical importance. Health care is sometimes referred to as "special," or different from other social goods, because of its necessity in enabling individuals to maintain the health and functioning that allow them to benefit from or enjoy other social goods such as education, employment, recreation, and social activities.").

I. CONTEXTUALIZING THE AFFORDABLE CARE ACT AND MEANINGFUL ACCESS TO MENTAL HEALTH CARE

The Affordable Care Act will expand mental health care, substance abuse benefits, and parity protections for approximately 62 million people, reflecting one of the largest expansions in behavioral health access in history.²⁷ Will these benefits reach those most in need of psychosocial supports? What are the primary barriers to meaningful access among culturally and linguistically diverse communities? Will the ACA produce substantive improvements in mental health by successfully traversing these barriers? Before presenting the ACA's key provisions related to mental health promotion, this Section first provides a snapshot of the evolution and limits²⁸ of "meaningful access" to health care as both a conceptual and remedial framework for processing the ACA's mental health agenda. I then discuss the bio-medical and social constructions of mental health, illness, and psychosocial disability in the United States. I highlight the theoretical flaws driving our current health care model's focus on individual deficits when seeking to generate broader substantive equality. Thereafter, I demonstrate the challenges experienced by Latinos, the largest and fastest growing culturally and linguistically diverse group in the United States.

A. Framing "Meaningful Access" to Mental Health Care

The ACA prioritizes the reduction in health disparities and improved health status—both physical and mental—among ethnically and racially diverse communities.²⁹ Civil rights advocates in the late 1960s and 1970s pushed—albeit unsuccessfully—for federal recognition of health care rights grounded in the Fourteenth Amendment.³⁰ The primary justification

27. KIRSTEN BERONIO ET AL., U.S. DEP'T OF HEALTH & HUMAN SERVS., AFFORDABLE CARE ACT EXPANDS MENTAL HEALTH AND SUBSTANCE USE DISORDER BENEFITS AND FEDERAL PARITY PROTECTIONS FOR 62 MILLION AMERICANS 1 (2013), available at http://aspe.hhs.gov/health/reports/2013/mental/rb_mental.cfm.

28. Scholars have discussed the tension between a civil rights framework, health law, and disability rights. See, e.g., Jessica L. Roberts, *Health Law as Disability Rights Law*, 97 MINN. L. REV. 1963, 1965 (2013) ("Although both the Rehabilitation Act and the ADA facially apply in health-care settings, those statutes have been ineffective at targeting these inequities because of their civil rights structure. The statutes' vulnerability to restrictive court interpretations, coupled with their focus on individual instances of discrimination, make civil rights law an inappropriate tool for challenging health disparities.").

29. ACA § 3011.

30. See, e.g., PAUL STARR, *THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE* 388-93 (1982) (discussing the inclusion of the "right to health care" as a part of the civil rights platform).

for its rejection was the claim of non-justiciability of “social rights” such as health, housing, and education.³¹ Nearly fifty years later—and after countless efforts to read such a right into the Constitution or generate affirmative legislation in this area—there is no federal right to health care.³²

Reframing disparities in mental health care among linguistically and culturally diverse communities as part of the broader doctrinal development of meaningful access to services offers particular insights into the limits of federal legislation and courts to capture and remedy the barriers at work in Isabel’s narrative. This doctrine of “meaningful access” evolved outside of the health law arena in the context of civil rights—primarily through Title VI³³ of the Civil Rights Act of 1964, Section 504 of the Rehabilitation Act,³⁴ and later, the Americans with Disabilities Act.³⁵ The hard fought victories of the civil rights era to eradicate explicit institutional racism—including the expansion of public safety nets and economic redistribution—made way for regulations and policies that did not produce the equality envisioned by civil rights leaders. Civil rights organizations—the leaders of which at the time recognized the law as a powerful vehicle for social justice—challenged legislation governing an array of public benefits including welfare,³⁶ education,³⁷ and health.³⁸ People of color, persons with disabilities, and linguistically diverse communities received clear messages that formal equality existed and barriers to access were individual exceptions. As such, individual remedies reflected special accommodations to what were widely perceived as normatively equitable

31. *But see* Kim Lane Scheppele, *A Realpolitik Defense of Social Rights*, 82 TEX. L. REV. 1921, 1921 (2003) (arguing for a recognition of such basic social rights).

32. The ACA, of course, is the closest actualized expression of such a universal right.

33. For example, Title VI of the Civil Rights Act of 1964 states that “[n]o person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.” 42 U.S.C. § 2000d. Title VI reaches both intentional discrimination and disparate impact and extends beyond the actual program or activity being funded to prohibit discrimination throughout entire agencies or institutions if any part of an agency or institution receives federal financial assistance. *See* Civil Rights Restoration Act of 1987, 20 U.S.C. § 1687-1688 (2002) (clarifying the expansive reach of Title VI to address the limitations imposed in *Grove City College v. Bell*, 465 U.S. 555 (1984), on Title IX discrimination cases).

34. Rehabilitation Act, 29 U.S.C. § 701 (1973).

35. 42 U.S.C. § 12101 et seq. (1990).

36. *See generally* *Goldberg v. Kelly*, 397 U.S. 254 (1970).

37. *See* *Lau v. Nichols*, 414 U.S. 563, 564 (1974); *Bd. of Educ. v. Rowley*, 458 U.S. 176, 209-10 (1982).

38. *Alexander v. Choate*, 469 U.S. 287 (1985).

institutions.

While judges may have recognized the disconnect between formal and substantive equality, they struggled with the limits of the law and doctrine to bridge this divide and give practical meaning to the notion of “access” to services. Frank Michelman described this judicial awareness as “not to equality, but to a quite different sort of value or claim that might better be called ‘minimum welfare.’”³⁹ “Meaningful access” fluctuated somewhere on a continuum between adequate access or “some benefit”⁴⁰ on one end, and an illusory (and judicially impermissible) “maximum benefit”⁴¹ at the other end, determined in accordance with the reasonableness of the fact pattern.⁴² Judicial opinions reflected a certain degree of arbitrariness, sequentially adopting poorly defined-notions of “meaningful” or “reasonable” from prior cases without sufficient clarity as to the obligatory floor or ceiling.⁴³

39. Frank I. Michelman, *The Supreme Court 1968 Term Foreword: On Protecting the Poor through the Fourteenth Amendment*, 83 HARV. L. REV. 7, 9 (1969-1970); see also Leslie Pickering Francis and Anita Silvers, *Debilitating Alexander v. Choate: “Meaningful Access” to Health Care for People with Disabilities*, 35 FORDHAM URB. L.J. 447, 447 (2008) (framing conversation in *Choate* and more broadly in the federal judiciary during this time as a move towards “equality of opportunity”).

40. See generally *Rowley*, 458 U.S. at 195.

41. *Id.* at 198.

42. *Choate*, 469 U.S. at 299 (examining the remedial reach of Section 504 of the Rehabilitation Act in disparate impact cases). Section 504 provided the drafters of the Americans with Disabilities Act with the foundational concepts (and, in some cases, language) to describe possible accommodations an individual with a disability might need in order to have an equal opportunity to participate in the workforce. The degree of “undue hardship” in the Rehabilitation Act, as well as in the ADA, established the outer limit of the employer’s obligation to provide such “reasonable accommodations.” See 42 U.S.C.S. § 12111 (10) (defining “undue hardship” as “an action requiring significant difficulty or expense” and enumerating factors for making such a determination); see also *U.S. Airways v. Barnett*, 535 U.S. 391, 400-02 (2002) (considering the plaintiff’s costs in the “reasonableness” calculation as distinguished from *Vande Zande*’s focus on the economic costs to the employer); *Vande Zande v. State of Wisc. Dep’t of Admin.*, 44 F.3d 538, 546 (7th Cir. 1996) (finding that an employer is not required “to expend even modest amounts of money to bring about an absolute identity in working conditions between disabled and nondisabled workers,” only “what is necessary to enable the disabled worker to work in *reasonable comfort*”) (emphasis added).

43. Such uncertainty did little to manage employers and employees rights and responsibilities with respect to the process of determining the reasonableness of a request for accommodations. What factors are most salient? Costs incurred by whom? Costs to the plaintiff seeking the accommodation or the employer? In *Vande Zande*, for example, Judge Posner’s analysis focuses on the cost efficacy of such a request for accommodation as the relevant (perhaps most important) consideration in the analysis. *Vande Zande*, 44.F.3d at 542-43. However, the opinion does not clarify the underlying

Judges rhetorically accepted “basic demands of subsistence, [which] can help bring within the reach of the poor the same opportunities that are available to others to participate meaningfully in the life of the community.”⁴⁴ While the Court recognized the existence of such “basic demands of subsistence,” it did not create an affirmative right to such support; rather, when the state chose to offer such “subsistence,” it had to do so in such a way as to allow for equitable access to such benefits.⁴⁵ The insights of critical race theorists⁴⁶ such as Derrick Bell, Alan Freeman, and Richard Delgado in the late 1970s did not reach this doctrinal discourse. Their collective demands for a contextual reading of the law and its institutions—which systematically oppressed the voices and experiences of people of color in the United States—went unheeded.⁴⁷

factors in such cost-benefit analysis and leaves the line between what constitutes “reasonable” as opposed to “unreasonable” sufficiently undefined. Samuel Bagenstos uses Judge Posner’s focus on cost efficacy in making reasonable accommodations as an example of the political will behind the ADA seeking to reduce the costs associated with public benefits for persons with disabilities. Samuel R. Bagenstos, *The Americans with Disabilities Act as Welfare Reform*, 44 WM. & MARY L. REV. 921, 927 (2003) (framing the ADA as antidiscrimination/anti-subordination laws intended to remove barriers to meaningful participation of persons with disabilities in the economy). Compare the denial of reasonable accommodation and cost-benefit analysis in *Vande Zande* with Judge Calabresi’s grant of more costly reasonable accommodation justified in economic terms in *Borkowski v. Valley Cent. Sch. Dist.*, 63 F.3d 131, 142 (2d Cir. 1995).

44. See generally *Goldberg v. Kelly*, 397 U.S. 254, 264 (1970).

45. *Id.*; see also *Dandridge v. Williams*, 397 U.S. 471, 486-87 (1970) (retreating from social rights worthy of equal protection by holding that the specific provisions of welfare benefits are subject to “rational basis review” with appropriate deference to states to determine the welfare of its citizens).

46. RICHARD DELGADO & JEAN STEFANCIC, *CRITICAL RACE THEORY: AN INTRODUCTION I* (2001) (defining critical race theory as “studying and transforming the relationship among race, racism, and power. The movement . . . places them in a broader perspective that includes economics, history, context, group-, and self-interest, and even feelings of the unconscious.”).

47. See Derrick A. Bell, Jr., *Serving Two Masters: Integration Ideals and Client Interests in School Desegregation Litigation*, 85 YALE L.J. 470, 504 (1976); DERRICK A. BELL, *RACE, RACISM, AND AMERICAN LAW* (Erwin Chemerinsky et al. eds., 5th ed. 2004); Richard Delgado, *When a Story is Just a Story: Does Voice Really Matter?*, 76 VA. L. REV. 95, 107 (1990); Richard Delgado, *The Imperial Scholar: Reflections on a Review of Civil Rights Literature*, 132 U. PA. L. REV. 561, 572 (1984); Alan D. Freeman, *Legalizing Racial Discrimination Through Antidiscrimination Law: A Critical Review of Supreme Court Doctrine*, 62 MINN. L. REV. 1049, 1070 (1977); Alan D. Freeman, *Racism, Rights and the Quest for Equality of Opportunity: A Critical Legal Essay*, 23 HARV. C.R.-C.L. L. REV. 295, 379 (1988); *Introduction to CRITICAL RACE THEORY: THE KEY WRITINGS THAT FORMED THE MOVEMENT*, at xvi (Kimberle Crenshaw et al. eds., 1995), available at

Courts, thereafter, expanded the doctrine of meaningful access to include language access in response to linguistic barriers preventing growing Latino and Asian populations⁴⁸ from enjoying equal opportunities to access public benefits. The Supreme Court held in *Lau v. Nichols*⁴⁹ that a group of Chinese-speaking students could not be denied access to educational programs because of their limited English proficiency status.⁵⁰ The Court reasoned that pursuant to Title VI of the Civil Rights Act language is a proxy for national origin and, therefore, “recipients of federal funding may be found liable for discrimination for failing to provide direct access to language services.”⁵¹ The Court distinguished between mere “access” and “meaningful access”: “there is no equality of treatment merely by providing students with the same facilities, textbooks, teacher, and curriculum; for students who do not understand English are effectively foreclosed from any *meaningful* education.”⁵² However, courts made clear distinctions between language and culture as barriers to meaningful access. Shortly after *Lau*, for example, the Ninth Circuit held that an Arizona school district’s failure to provide bicultural education—as opposed to bilingual education—did not deny Mexican American and Yaqui Indian parents and their children an opportunity to meaningfully access public education.⁵³

The Americans with Disabilities Act⁵⁴ and the Individuals with Disabilities Education Act⁵⁵ both echoed and affirmatively shaped public

http://www.temple.edu/tempres/chapters_1100/1169_ch1.pdf.

48. Population swells stem in part from the comprehensive immigration reform Immigration and Nationality Act of 1965—e.g., family unification provisions.

49. See *Lau v. Nichols*, 414 U.S. 563, 563 (1974).

50. *Id.*

51. *Id.*

52. *Id.* at 566 (emphasis added).

53. *Guadalupe Org. v. Tempe Elementary Sch. Dist.*, 587 F.2d 1022, 1029-30 (9th Cir. 1978).

54. American with Disabilities Act (ADA) of 1990, 42 U.S.C. § 12101 (“It is the purpose of this chapter . . . to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.”).

55. Congress amended the Education for All Handicapped Children Act of 1975 (Public Law 94-142) in 1990, renamed and replaced it with the Individuals with Disabilities Education Act. Congress has subsequently amended and reauthorized the IDEA, most notably in 2004. 20 U.S.C. § 1400 (2006) (“Congress finds the following: Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-

opinion in favor of assimilation and mainstream inclusion. Judicial opinions interpreting these Acts maintained the default presumption that the law and its institutions were inherently equitable yet reasonable accommodations might be necessary in some situations to provide individuals with an equal opportunity to benefit from particular public services or benefits. Accordingly, federal courts found violations of meaningful access to services on behalf of persons with HIV/AIDS seeking to access public benefits to remain integrated in society,⁵⁶ students with disabilities seeking to protect placement in a mainstream school setting through reasonable accommodations,⁵⁷ persons with sight impairments seeking to use guide dogs to maintain independence,⁵⁸ and a deaf and mute prisoner seeking a sign language interpreter to meaningfully participate in disciplinary proceedings.⁵⁹

In 2001, the results of a study commissioned by the U.S. Surgeon General to identify solutions to health care disparities rhetorically revealed the much earlier insights of critical race theorists regarding meaningful access:

sufficiency for individuals with disabilities.”).

56. *Henrietta D. v. Giuliani*, 119 F. Supp. 2d 181, 209 (E.D.N.Y. 2000) (“[D]efendants are failing to make the reasonable accommodations necessary to ensure plaintiffs meaningful access to, and an equal opportunity to benefit from, the social welfare benefits and services that defendants provide to eligible New York City residents.”).

57. *Cedar Rapids Cmty. Sch. Dist. v. Garret F.*, 526 U.S. 66, 73 (1999) (“As a general matter, services that enable a disabled child to remain in school during the day provide the student with ‘the meaningful access to education that Congress envisioned.’”) (citations omitted).

58. *Crowder v. Kitagawa*, 81 F.3d 1480, 1484 (9th Cir. 1996) (“Although Hawaii’s quarantine requirement applies equally to all persons entering the state with a dog, its enforcement burdens visually-impaired persons in a manner different and greater than it burdens others. Because of the unique dependence upon guide dogs among many of the visually-impaired, Hawaii’s quarantine effectively denies these persons—the plaintiffs in this case—meaningful access to state services, programs, and activities while such services, programs, and activities remain open and easily accessible by others. The quarantine, therefore, discriminates against the plaintiffs by reason of their disability.”).

59. *Randolph v. Rodgers*, 170 F.3d 850, 858 (8th Cir. 1999) (“The Department of Corrections argues strenuously that Randolph was not excluded from prison services, programs, and activities. It is true that Randolph could physically attend activities. However, the ADA and RA require that otherwise qualified individuals receive ‘meaningful access’ to programs and activities.”).

[w]hile mental disorders may touch all Americans either directly or indirectly, all do not have equal access to treatment and services Critically, culture counts. That means we need to embrace the nation's diversity in the conduct of research, in the education and training of our mental health service providers and in the delivery of services.⁶⁰

Unfortunately, the Surgeon General's subsequent public policy initiatives continued to focus narrowly on language access as a proxy for cultural competency in the delivery of mental health care, thereby missing an opportunity to explore the hidden barriers impeding improvements in mental health status.⁶¹

That same year, in response to a growing language access movement, President Bill Clinton signed Executive Order 13166, "Improving Access to Services for Persons with Limited English Proficiency," requiring Federal agencies to ensure that recipients of Federal financial assistance provide meaningful access to their LEP applicants and beneficiaries.⁶² Language access continued to test the bounds of meaningful access in the courts. Rather than expanding protections against national origin or racial discrimination under civil rights statutes to include failures to provide culturally competent services, for example, courts adopted a narrow view of national origin discrimination and limited formal protections to language access alone.⁶³

Questions remain regarding the role of courts in remedying cultural barriers to meaningful access of federal (or federally-funded) programs or services. If cultural competency is framed as a matter of "disparate impact," then the legal remedies available are limited at the federal level.⁶⁴

60. Damon Thompson, *Culture Counts in Mental Health Services and Research Finds New Surgeon General Report*, SURGEON GEN., (2001) <http://www.surgeongeneral.gov/news/2001/08/cre.html>.

61. At the time the Surgeon General released his report, more than 47 million people in the United States spoke a language other than English at home and almost 3 million reported no knowledge of the English language. HYON B. SHIN & ROSALIND BRUNO, U.S. CENSUS BUREAU, LANGUAGE USE AND ENGLISH-SPEAKING ABILITY: 2000, at 4 (2003).

62. See Exec. Order No. 13, 166, 65 Fed. Reg. 50, 121 (Aug. 11, 2000); see also Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons, 67 Fed. Reg. 41,455 (proposed June 18, 2002).

63. Ikemoto, *supra* note 12, at 127.

64. *Alexander v. Sandoval*, 532 U.S. 275, 307 (2001). *But see* Leslie Pickering Francis and Anita Silvers, *Debilitating Alexander v. Choate: "Meaningful Access" to Health Care for People With Disabilities*, 35 FORDHAM URB. L.J. 447, 447 (2008) ("In this Article, we develop a strategy for addressing and, we hope ultimately, circumscribing Choate's influence and debilitating its effects [by interpreting the standard as 'equality of opportunity.']").

The absence of a federal constitutional or statutory right to health or health care limits the feasibility of a judicial remedy for a denial of access to health care. The Affordable Care Act does not remedy these deficiencies despite moving the nation towards greater access in the aggregate.

Meaningful access to mental health care must include improvements in mental health status among culturally and linguistically diverse communities. To achieve meaningful access, therefore, states in particular must engage in a critical analysis of models of health care delivery and supports, and surrounding regulatory structures. The next sections weave into this discussion the complexities of mental health care delivery in the United States and the gravity of the disparities in mental health care among Latinos.

B. Mental Health, Illness, and the Medical Model of Mental and Psychosocial Disabilities in the United States

The subjectivity and ambiguity associated with defining and diagnosing mental illness and mental health in the United States complicate any legal analysis of meaningful access to health care. Such inexactitude has generated much criticism as to whether mental and psychosocial disabilities are all socially constructed and imprecise, subjective manifestations of deviant, irrational behaviors; or grounded in etiology and attributable to abnormal physiological or chemical conditions in the body; or somewhere on a continuum between the two. The importance of this debate guides our understanding of whose values are normalized and promoted and whose are pathologized and marginalized.

Mental health and illness are not polar opposites;⁶⁵ instead, they represent different points on an ever-fluctuating continuum that shifts according to life experiences and stressors as experienced by both the evaluator and person evaluated. The American Psychiatric Association has noted that the term “mental disorder” itself is problematic because it “implies a distinction between ‘mental’ and ‘physical’ disorders that is a

65. The binary distinction between mental health and illness is somewhat analogous to the problematic move in medical history, which divides mental and physical health as if they are distinct and severable. *See, e.g.*, RENE DESCARTES, MEDITATIONS X (1641) (“To commence this examination accordingly, I here remark, in the first place, that there is a vast difference between mind and body, in respect that body, from its nature, is always divisible, and that mind is entirely indivisible.”). Descartes viewed the mind (spiritual domain) as separate from the body (medical domain) in part because it was simply the most reasonable hypothesis available in a time of limited or emerging scientific knowledge. Further, the ability to compartmentalize the two allowed for medical specialization and definition of a distinct scope of practice which, in turn, may have been driven by a need for social hierarchies and stratification.

reductionist anachronism of mind/body dualism. A compelling literature documents that there is much ‘physical’ in mental disorder and much ‘mental’ in physical disorder.”⁶⁶ Interestingly, while the Diagnostic and Statistical Manual of Psychiatric Disorders (“DSM”), the bedrock of modern psychiatric medicine, explicitly defines mental illness, it offers no definition or discussion of “mental health.”⁶⁷ This absence certainly reflects the difficulty in defining the components of mental well-being, in part, because what it means to be mentally healthy is subject to many different (and perhaps at times conflicting) interpretations rooted in judgments that may vary across different cultures.

The skills and attributes advanced in psychology and behavioral science are heavily embedded in Western ideology that tends to depict the “mentally healthy person” as an autonomous, self-actualizing person with independent self-coping skills sufficient to respond to environmental stressors. This view challenges efforts at mental health promotion aimed at both individual and structural reform, which demands involvement of people as full participants in problem identification and solution generation, and not simply as passive recipients of care.

While no single theory of mental illness dominated the field prior to World War II,⁶⁸ mental disability consistently signaled a personal deficit—an inability to cope with the stressors of life. Psychiatry, in turn, increasingly relied on chemical and biological causes of, and treatments for, mental illness, which led to greater marginalization of other kinds of therapeutic interventions. The biological origins of mental illness that dominated medical practice from the 1950s on have been memorialized in the DSM.

Whether or not an individual has a mental disability recognized by the DSM is a highly relevant question in assessing legal rights to non-discrimination, reasonable accommodations, special education services, income support, and more intensive forms of services supported by the Medicaid program. The DSM serves as the basis of mental health law for

66. See AM. PSYCHIATRIC ASS’N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS, at xxi (4th ed. 2000). The complexity surrounding the origins and current state of the mental-physical divide is beyond the scope of this paper.

67. *Id.* (stating that a “clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with present distress or disability or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom.”); see, e.g., JONATHAN M. METZEL, AGAINST HEALTH: HOW HEALTH BECAME THE NEW MORALITY 2-5 (Jonathan M. Metzel & Anna Kirkland eds., 2010) (discussing the role of “health promotion” in exacerbating stigma for certain individuals deemed to fall outside of the norm of health).

68. METZEL, *supra* note 67, at 189.

courts,⁶⁹ regulatory agencies,⁷⁰ schools,⁷¹ social services,⁷² prisons,⁷³ and

69. A label of “mental illness” has legal significance when it is “invoked to justify the deprivation of a fundamental liberty or to excuse an individual from what otherwise would constitute a crime [and such] definition must be legal, not clinical.” Bruce J. Winick, *Ambiguities in the Legal Meaning and Significance of Mental Illness*, 1 PSYCHOL. PUB. POL’Y & L. 534, 538 (1995); see also Daina C. Chiu, *The Cultural Defense: Beyond Exclusion, Assimilation, and Guilty Liberalism*, 82 CALIF. L. REV. 1053, 1112-13 (1994) (discussing “cultural defenses,” the notion that a criminal defendant may act in ways consistent with the laws and traditions of her native country or culture and that such cultural considerations may not excuse behavior criminalized in the U.S. but are relevant to determination of state of mind or intent, or perhaps mitigating factors around charging and sentencing); Carolyn Choi, Note, *Application of a Cultural Defense in Criminal Proceedings*, 8 PAC. BASIN L.J. 80, 84 (1990) (citing *People v. Moua*, No. 315972 (Cal. Super. Ct. Fresno Cnty. Feb. 7, 1985)) (discussing a successful invocation of the cultural defense where criminal charges were reduced from kidnapping and rape to false imprisonment for Hmong defendant considering traditional Hmong marriage tradition—“zij pojniam” (marriage by capture)—which calls for the woman to protest the man’s sexual advances and for him to continue despite protest to show his strength and worthiness as a husband).

70. See Thomas Laughren et al., *FDA Perspective on the DSM-5 Approach to Classification of “Cognitive” Disorders*, 23 J. NEUROPSYCHIATRY & CLINICAL NEUROSCIENCES 126, 126 (2011) (discussing the interrelationship between the classification of disorders in the DSM and the FDA approval process for new drugs that treat those disorders).

71. Individuals with Disabilities Education Act (IDEA), 20 U.S.C. § 1401(3)(A) (defining “a child with a disability” to include the following categories: “intellectual disabilities, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities.”); see also Johnny L. Matson et al., *DSM-IV vs. DSM-5 Diagnostic Criteria for Toddlers with Autism*, 15 DEVELOPMENTAL NEUROREHABILITATION 185, 185-90 (2012) (discussing how proposed revisions to the DSM could result in less children being diagnosed with autism spectrum disorders and thus render fewer children eligible for related services); Johnny L. Matson et al., *How Does Relaxing the Algorithm for Autism Affect DSM-V Prevalence Rates?*, 42 J. AUTISM & DEVELOPMENTAL DISORDERS 1549, 1555 (2012) (explaining the possible implications of changes to the DSM diagnostic criteria for families of children with autism symptomology).

72. See, e.g., *Chisholm v. Kliebert*, No. 97-3274, 2013 WL 4249267 (E.D. La. Aug. 13, 2013) (discussing the implications of the DSM-5 on Medicaid determinations).

73. See PAULA M. DITTON, U.S. DEP’T OF JUSTICE, BUREAU OF JUSTICE STATISTICS SPECIAL REPORT: MENTAL HEALTH AND TREATMENT OF INMATES AND PROBATIONERS 2 (1999) (reporting that 16% of people in state prisons have a diagnosed, DSM-classified psychosocial disorder); see, e.g., *Woodward v. Corr. Med. Servs.*, 368 F.3d 917, 927 (7th Cir. 2004) (addressing deliberate indifference to a prisoner’s medical needs in the context of a mentally ill prisoner who committed suicide); *Kosilek v. Maloney*, 221 F. Supp. 2d 156, 184 (D. Mass. 2002) (relying on the definition of gender identity

drug companies.⁷⁴ Both public and private entities have translated its diagnostic categories into reimbursable codes for receipt of benefits,⁷⁵ treatment, and research funding.⁷⁶

This emphasis on biological etiology defines the medical model of disability. Critics of the medical model decry medical professionals' role in reducing an individual to her disability in an effort to cure or rehabilitate her.⁷⁷ Persons with disabilities are socially positioned as persons in need of public assistance, pity, and charity.⁷⁸ Disability rights scholars introduced

disorder in the DSM to conclude that it would violate the Eighth Amendment's prohibition on cruel and unusual punishment if an inmate suffering from gender identity disorder were to be prevented from receiving appropriate medical care, which in this case included gender-reassignment surgery); *see also* FRED OSHER ET AL., COUNCIL OF STATE GOV'TS JUSTICE CTR. & CRIMINAL JUSTICE/MENTAL HEALTH CONSENSUS PROJECT, ADULTS WITH BEHAVIORAL HEALTH NEEDS UNDER CORRECTIONAL SUPERVISION: A SHARED FRAMEWORK FOR REDUCING RECIDIVISM AND PROMOTING RECOVERY 8 (2012), *available at* http://www.asca.net/system/assets/attachments/4908/9.27.12_Behavioral_Framework_v6_full.pdf?1348755628 (illustrating the additional resources required to treat individuals with psychosocial needs such as in Broward County Jail in Florida, where the daily inmate cost is \$78, but the cost rises to \$125 per day for inmates with mental illness).

74. *See* Lisa Cosgrove et al., *Financial Ties Between DSM-IV Panel Members and the Pharmaceutical Industry*, 75 *PSYCHOTHERAPY & PSYCHOSOMATICS* 154, 154-60 (2006) (discussing the financial implications of the diagnostic criteria for mental disorders to the pharmaceutical industry).

75. Accordingly, “[y]ou need a diagnosis to bill—that’s the way the world works . . . you can’t just treat somebody without giving them a formal diagnosis . . . [As a result] the DSM has become the tail that wags the dog.” Jay Neugeboren, *The Consolidation of a Psych Diagnosis*, ATLANTIC (May 8, 2013), <http://www.theatlantic.com/health/archive/2013/05/the-consolation-of-a-psych-diagnosis/275608> (quoting Frank Putnam from the Children’s Hospital Medical Center in Cincinnati, Ohio).

76. *See, e.g.*, AM. PSYCHIATRIC ASS’N, INSURANCE IMPLICATIONS OF DSM-5, *available at* <http://www.psychiatry.org/File%20Library/Practice/DSM/DSM-5/Insurance-Implications-of-DSM-5.pdf> (indicating that the DSM-5 is consistent with the ICD-9-CM coding system utilized by insurance companies). *But see* Thomas Insel, *Director’s Blog: Transforming Diagnosis*, NAT’L INST. OF MENTAL HEALTH, (Apr. 29, 2013), <http://www.nimh.nih.gov/about/director/2013/transforming-diagnosis.shtml> (indicating that the National Institute of Mental Health will no longer base research grants on DSM criteria).

77. *See, e.g.*, MICHAEL OLIVER, *THE POLITICS OF DISABLEMENT: A SOCIOLOGICAL APPROACH* 11 (1990) (explaining the “social model” and contrasting it with the historical construction of the “medical model” of disability); *see also* MICHAEL OLIVER, *UNDERSTANDING DISABILITY: FROM THEORY TO PRACTICE* 19-42 (1996); Samuel R. Bagenstos, *Subordination, Stigma, and “Disability,”* 86 *VA. L. REV.* 397, 426-436 (2000).

78. Bagenstos, *supra* note 77, at 427; *see also* MARY JOHNSON, *MAKE THEM GO*

the “social model” of disability which, according to Samuel Bagenstos, “[in its entirety] can be seen as a reaction to that ‘medical/pathological paradigm’ of disability.”⁷⁹ The social model adopts what Martha Minow calls the “social relations” approach to difference where disability is the interaction between societal barriers and a particular physical or mental impairment.⁸⁰

The focus on society’s role in constructing disability does not ignore the presence of a mental or physical impairment;⁸¹ rather, the social model presents a dichotomy: “disablement”—reflecting the social constructions of disability—and “impairment”—reflecting a physiological condition. One scholar has recently challenged this binary conception arguing that impairments themselves are social constructions.⁸² The political and financial incentives underlying the DSM’s fluctuating diagnostic categories⁸³ support this view of constructed “impairments.” Empirical studies have unearthed additional evidence of the subjectivity and arbitrariness in diagnostic classification.⁸⁴

AWAY: CLINT EASTWOOD, CHRISTOPHER REEVE AND THE CASE AGAINST DISABILITY RIGHTS 27 (2003). *See generally* JOSEPH SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT (1994).

79. *See, e.g.*, HARLAN HAHN, CIVIL RIGHTS FOR DISABLED AMERICANS: THE FOUNDATION OF A POLITICAL AGENDA, IN IMAGES OF THE DISABLED, DISABLING IMAGES 181, 183-84 (Alan Gartner & Tom Joe eds., 1987).

80. MARTHA MINOW, MAKING ALL THE DIFFERENCE: INCLUSION, EXCLUSION, AND AMERICAN LAW 110-114 (1990) (discussing the social relations approach to understanding and processing difference).

81. Some scholars have criticized the absence of actual physical impairments in the discussion of the social model of disability. *See, e.g.*, Kevin Paterson, *The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment*, 12 DISABILITY & SOC. 325, 325 (1997).

82. Bradley A. Areheart, *Disability Trouble*, 29 YALE L. & POL’Y REV. 347, 363 (2011) (“[D]iagnosis is a social concept in at least two tangible ways. First, acceptable categories of diagnoses are created by a variety of non-medical factors and take form as interested parties interact. The very existence of many impairments is thus largely contingent upon political and social factors. Second, the actual process of diagnosing an individual includes various social inputs that assist the medical professional in concluding that a person has a particular impairment.”).

83. *See, e.g.*, Lisa Cosgrove et al., *Financial Ties Between DSM-IV Panel Members and the Pharmaceutical Industry*, 75 PSYCHOTHERAPY & PSYCHOSOMATICS 154, 156 (2006) (providing empirical evidence of the pivotal role of pharmaceutical companies in shaping diagnostic categories by showing blatant conflicts of interest between panel members and pharmaceutical companies).

84. *See, e.g.*, Lars Noah, *Pigeonholing Illness: Medical Diagnosis as a Legal Construct*, 50 HASTINGS L.J. 241, 248 (1999) (“Mental health professionals often express greater disagreements about an appropriate diagnosis for a particular patient because the relevant symptoms tend to be non-specific, which means that any number

The history of mental health and illness in the United States is highly racialized and gendered. The “science” of medicine and psychiatry has been used as a means of social control. Although the narratives of women and people of color as survivors of early psychiatric care are not well-documented—in part because documentation itself holds power to educate, connect, and transform⁸⁵—the literature reveals the construction of culturally-specific, gender-specific, and racially-specific disorders to justify institutional exclusion.⁸⁶ For example, women have been the subject of disproportionate psychoanalysis and treatment focused on their deviation from male constructed and defined norms:

Psychiatrists and psychologists have traditionally described the signs and symptoms of various kinds of real and felt oppression as mental illness. Women often manifest these signs, not only because they are oppressed in an objective sense, but also because the sex role (stereotype) to which they are conditioned [hyper-emotional and reactive] is composed of just such signs.⁸⁷

Historically, psychiatric medicine has produced social and cultural constructs of women, their behaviors, and their bodies,⁸⁸ which, in turn,

of mental illnesses could account for the particular complaint.”).

85. See generally Carrie Menkel-Meadow, *Portia in a Different Voice: Speculation on a Women's Lawyering Process*, 1 BERKELEY WOMEN'S L.J. 39 (1985) (discussing the power of women's increased presence in the practice of law to transform the narrative and process of knowledge collection).

86. See, e.g., PHYLLIS CHESLER, *WOMEN AND MADNESS* 269 (2005) (“What have contemporary American psychologists and psychiatrists thought and felt about feminism? Publicly, they have behaved as any other group: they have engaged in nervous laughter, purposeful misunderstanding, hairsplitting, malicious cruelty, misguided sympathy, boredom, hostility, condensation, and commercial and academic capitalism.”); Derek H. Suite et al., *Beyond Misdiagnosis, Misunderstanding, and Mistrust: Relevance of the Historical Perspective in the Medical and Mental Health Treatment of People of Color*, 99.8 J. NAT'L MED. ASS'N 879, 881 (2007) (discussing “drapetomania,” a “severe” mental illness “discovered” by Dr. Samuel A. Cartwright in the late 19th century, which was characterized by “African slaves’ uncontrollable urge to escape slavery, destroy property on the plantation, be disobedient, talk back, fight with their masters and refuse to work.”).

87. Phyllis Chesler, *Women as Psychiatric and Psychotherapeutic Patients*, 33 J. MARRIAGE & FAM. 746, 752 (1971).

88. Caroline Ruth Smith, *A Feminist Analysis of Mental Health Providers' Perspective of Latina Women* (June 2010) (unpublished M.A. thesis, DePaul University) (on file with DePaul University Library), available at <http://via.library.depaul.edu/cgi/viewcontent.cgi?article=1023&context=etd>. Examples of some of the more overtly gendered practices in the development of mental health theory and practice uncovered by feminist scholars include those that (1) judged traits traditionally associated with women such as nurturing and affability as less typical of a healthy person than those associated with men such as dominance and independence; (2) attributed more negative stereotypes to poor women or women of color than to

have been reinforced by the law.⁸⁹

C. The Social Context for Mental Health Care Reform

Approximately one in two people living in the United States will experience a psychosocial disability in their lifetime and about one in three will experience substance abuse.⁹⁰ With such sobering statistics, why focus on Isabel and on Latinos to illustrate the problems in health care delivery? The Latino experience has broad applicability for at least three reasons. First, Latinos are the largest ethnic and racial minority in the United States at close to seventeen percent of the U.S. population, and are projected to comprise thirty percent of the U.S. population by 2050 (133 million people). Second, Latinos represent a mix of new immigrants, for whom knowledge of English may be limited, and long-settled generations who fall somewhere between bilingual and monolingual (English only). Third, Latinos, like Asian communities in the United States, have largely resisted classic models of cultural assimilation applied to European immigrants, perhaps as a function of a more recent and steadier stream of immigration. As a result, Latinos have largely retained strong cultural traditions even when English becomes their dominant or preferred language. In this way, the analysis in this Article can be applied to other culturally and linguistically diverse communities in the United States.

The incidence of psychosocial disabilities and substance abuse disproportionately affects Latinas.⁹¹ These challenges are not the most

middle-class white women; (3) “attributed legitimate reports of women’s distress to biology or intrapsychic disorder rather than to external causes such as those related to power inequities and discrimination in the socio-cultural environment.” *Id.*

89. At a minimum, the law has historically insulated the medical professional from reproach through systemic deference to medical opinion—e.g., as an evidentiary matter in civil commitment cases, custody cases, and criminal matters. *See, e.g.*, Fed. R. Crim. P. 12.2 (Notice of Insanity Defense; Mental Examination); Fed. R. Evid. 703 (Bases of an Expert’s Opinion Testimony); *see also* Christopher Slobogin, *Psychiatric Evidence in Criminal Trials: To Junk or Not to Junk?*, 40 WM. & MARY L. REV. 1, 13 (1998). Criminal law and its procedural rules, for example, have collaborated successfully to suppress and delegitimize women’s experiences of rape. *See generally* Mary Joe Frug, *A Postmodern Feminist Legal Manifesto (An Unfinished Draft)*, 105 HARV. L. REV. 1045 (1992) (commenting on the power of legal rules to excuse and, at other times, mandate the sexualization of women’s bodies).

90. DEANNA OKRENT, TESTIMONY AT BEHAVIORAL HEALTH BRIEFING, ALLIANCE FOR HEALTH REFORM 67 (2012), *available at* <http://www.allhealth.org/briefingmaterials/050412-alliancebehavioralhealthtranscriptdited-2297.pdf>.

91. SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., U.S. DEP’T OF HEALTH & HUMAN SERVS., RESULTS FROM THE 2009 NATIONAL SURVEY ON DRUG USE AND HEALTH: MENTAL HEALTH FINDINGS 99 (Dec. 2010), *available at* <http://www.samhsa.gov/data/NSDUH/2k9NSDUH/MH/2K9MHRResults.pdf>.

severe mental health disorders requiring aggressive intervention (e.g., acute cases leading to hospitalization or commitment). Rather, public health officials contend that Latinas are at greatest risk for depression and anxiety, which when left untreated and absent mitigation, quickly become greater sources of physical and mental stress, loss of employment and livelihood. Prevalence of depression is higher among Latina women (46%) than among Latino men (19.6%).⁹² Fewer than one in eleven Latinos with psychosocial disabilities contact mental health specialists, and fewer than one in five contact primary care providers.⁹³ Even among Latinos who access some form of mental health service, approximately sixty percent to seventy-five percent fail to return for a second session.⁹⁴ Alcohol abuse⁹⁵ and suicide rates among adolescent Latinas are significantly higher than those of non-Latino whites. Suicide rates among adolescent Latinas are sixty percent higher than the suicide rates of their non-Latina white counterparts; for example, every year, nineteen percent of all Latinas in high school attempt suicide at least once.⁹⁶ Further, Latinas are at increased risk for health problems that complicate mental and psychosocial disabilities, such as obesity, diabetes, and certain types of cancer.⁹⁷

Documented inequities in access to and receipt of quality mental health

92. Latino Comm. Mental Health Fact Sheet, NAT'L ALLIANCE ON MENTAL ILLNESS, (2006), http://www.nami.org/Template.cfm?Section=Fact_Sheets1&Template=/ContentManagement/ContentDisplay.cfm&ContentID=99516.

93. SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., *supra* note 10, at 29.

94. C. Barrio et al., *Serving Latino Families Caring for a Person with Serious Mental Illness*, in *CREATING INFRASTRUCTURES FOR LATINO MENTAL HEALTH* 159, 164 (L.P. Buki & L.M. Piedra eds., 2011).

95. Young Latinas have the highest rate of alcohol abuse (defined as five or more drinks at a time) at 36%, as compared to non-Latino whites at 32% and African Americans at 13%. Barbara Guthrie, Powerpoint Presentation, At the Crossroads: Adolescent Girl's Substance Use and Abuse, *available at* http://womenandchildren.treatment.org/documents/conference/ml_guthrie-508v.pdf (last visited Oct. 8, 2013).

96. NAT'L CTR. FOR INJURY PREVENTION & CONTROL, VIOLENCE PREVENTION, CTRS. FOR DISEASE CONTROL & PREVENTION, *SUICIDE FACTS AT A GLANCE* (2012), *available at* http://www.cdc.gov/violenceprevention/pdf/suicide_datasheet_2012-a.pdf.

97. Humberto Marin et al., *Mental Illness in Hispanics: A Review of the Literature*, 4 FOCUS 23, 26 (2006). For example, Latinas have disproportionate rates of cervical cancer at 1.6 times the rate of white women. *Cancer Health Disparities*, NAT'L CANCER INST., <http://www.cancer.gov/cancertopics/factsheet/disparities/cancer-health-disparities> (last visited Oct. 8, 2013). Studies have linked depression and anxiety with heart disease, Type 2 diabetes, renal disease, obesity, and asthma in Latinos living in the United States. Alexander N. Ortega et al., *Co-Occurrence of Mental and Physical Illnesses in U.S. Latinos*, 41 SOC. PSYCHIATRY & PSYCHIATRIC EPIDEMIOLOGY 927, 934 (2006). Data also exist to suggest that people with comorbid physical and mental illness have higher health care costs than people without such comorbidities. *Id.*

care among Latinos reflect broader structural inequities in access to economic, educational, and social opportunities in the Latino community that have a negative effect on mental health.⁹⁸ For example, Latinos living below the poverty level, as compared to Latinos over twice the poverty level, are three times more likely to report psychological distress.⁹⁹ The poverty rate for Latinos is 23.2%, affecting more than 11 million people.¹⁰⁰ Compared with non-Latino whites, the racial/ethnic disparity in both income and education was greatest for Latinos and non-Latino indigenous populations.¹⁰¹ Mental health problems experienced by the Latino community are exacerbated by the disparate impact of certain physical illnesses and poor environmental conditions, such as stress, economic insecurity, and failing schools. Latinos with diagnosed or under-diagnosed mental and psychosocial disabilities have disproportionate contact with the adult and juvenile criminal justice systems¹⁰² and, as a result, have disproportionately higher rates of detention and imprisonment than whites.¹⁰³

Indirectly, Latinas' role within the family and community as caregivers

98. Also, Latinos' history of institutional discrimination by and exclusion from U.S. institutions is a significant deterrent from utilizing formal care and government services. For example, in California, anti-immigrant attitudes, behaviors, and policies have distanced Latinos from the health care system generally and have resulted in greater emergency room use. Joshua J. Fenton et al., *Effect of Proposition 187 on Mental Health Service Use in California: A Case Study*, 15.1 HEALTH AFFS. 182, 186 (1996).

99. U.S. Dep't of Health & Hum. Servs., Office of Minority Health, Data and Statistics: Mental Health and Hispanics, <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=3&lvlID=9&ID=6477> (last visited Jan. 11, 2014).

100. SUZANNE MACARTNEY ET AL., U.S. CENSUS BUREAU, POVERTY RATES FOR SELECTED DETAILED RACE AND HISPANIC GROUPS BY STATE AND PLACE: 2007-2011, at 8-9 (Feb. 2013), *available at* <http://www.census.gov/prod/2013pubs/acsbr11-17.pdf>. The poverty rate for Latinos is more than nine percentage points higher than the overall U.S. rate of 14.3%. *Id.* at 3. Latino poverty rate varies when disaggregated by national/ethnic origin—between 16.2% for Cubans to a high of 26.3% for Dominicans. *Id.* at 2. Starker disparities arise when further disaggregated by state and city. For example, the highest poverty rate for Latinos reached upwards of 30% in Alabama, Arkansas, Georgia, North Carolina, and Rhode Island. *Id.* at 8.

101. CTRS. FOR DISEASE CONTROL & PREVENTION, FACT SHEET: HEALTH DISPARITIES IN EDUCATION AND INCOME (2011), *available at* <http://www.cdc.gov/minorityhealth/reports/CHDIR11/FactSheets/EducationIncome.pdf>

102. FRANCISCO A. VILLARRUEL ET AL., INSTITUTE FOR CHILDREN, YOUTH, AND FAMILIES, ¿DÓNDE ESTÁ LA JUSTICIA? A CALL TO ACTION ON BEHALF OF LATINO AND LATINA YOUTH IN THE U.S. JUSTICE SYSTEM 27-28 (2002) (demonstrating that there is disparate treatment of Latino and Latina youth in the American justice system).

103. *Id.*

places health care decision-making within their sphere of responsibility. It is therefore important to understand Latinas' help-seeking behaviors regarding mental health, their definitions of and ideas about mental and psychological disabilities, and their attitudes to utilization of mental health services not only for Latinas themselves, but also for other members in their households (e.g., partners, children, family members).

This section framed the current legal indeterminacy with respect to what constitutes "meaningful access" to public and, in the disability context, private services. The current meaningful access jurisprudence does not provide a clear, legally cognizable claim for Isabel on the basis of Dr. Smith's cultural incompetency highlighted in the opening narrative. The point of this Article is not to construct such a claim, but rather to identify the limits of the ACA as a vehicle to improve meaningful access to mental health for people such as Isabel. The muddiness of the meaningful access jurisprudence reflects the limitations of traditional antidiscrimination paradigms to capture the experiences of culturally and linguistically diverse communities. Equal opportunity to benefit from health care reform means more than market access; it demands a more complex understanding of institutional biases experienced by marginalized communities, the recognition of multiple narratives of illness and care, and engagement with and investment in natural support networks.

II. THE ACA'S MENTAL HEALTH GOALS AND STRUCTURAL REFORMS

The ACA reflects Congress' focus on costs and availability of affordable insurance as the main barriers to accessing and receiving health care. While cost is certainly a significant component, improved mental health among linguistically and culturally diverse communities requires more complex solutions. Part I's conclusion raises the question of the ACA's ability to remedy Isabel's challenges given doctrinal limitations and the tension between historical bio-medical constructions of mental disabilities focused on curing individual deficits and social models of disability.

This section focuses on the ACA itself—the development of its mental health goals, the social phenomena driving these goals, and the relevant provisions purportedly effectuating meaningful access. The ACA strives to transform all phases of the health care experience—input/threshold access; the process of health care delivery; and output (improved health outcomes). This section discusses the primary goal advanced by the ACA at each major point of interaction between the help seeker and the health care system, and the major provisions related to each goal. Specifically, the ACA seeks to: (1) expand access to health insurance and the scope of coverage to include mental health (an input); (2) increase the quality of services and the delivery of care (the process); and (3) improve mental

health outcomes (an output). These three areas of reform are interdependent. Improved health outcomes largely depend on the ACA's success in the first two stages of improving access and quality of health care delivery.

A. Focusing on Insurance: Access to and Scope of Coverage

The focus on equal access to health insurance is the heart and soul of the ACA. In addition to the central initiatives and provisions discussed below, the ACA invests significant resources in the accessibility and quality of public information on the new requirements. For example, the ACA has expanded an entire workforce of trained “patient navigators”¹⁰⁴ to engage in community outreach and public education (in multiple languages) and connect communities with new rights and responsibilities under the ACA. Most recently, the Department of Health and Human Services (“HHS”) issued regulations guiding the implementation of outreach initiatives. The regulations also specify the importance of “meaningful access” for LEPs and persons with disabilities to information regarding eligibility and the state exchanges, including the official ACA-established website,¹⁰⁵ ACA call centers,¹⁰⁶ patient navigators, “all applications, forms, and notices,”¹⁰⁷ and a provider network.¹⁰⁸

1. Expanding Access to Health Insurance

In 2011, 48 million non-elderly people were uninsured; one in three of

104. 42 U.S.C. § 256a(b) (2010).

105. Patient Protection and Affordable Care Act; Establishment of Exchanges and Qualified Health Plans; Exchange Standards for Employers, 77 Fed. Reg. 18,309, 18,447 (Mar. 27, 2013) (to be codified at 45 C.F.R. § 155.120) (“We also proposed that the Exchange Website be accessible to persons with disabilities and provide meaningful access to persons with limited English proficiency.”).

106. *Id.* at 18,327 (“We have amended the final rule to apply the meaningful access standards specified in the redesignated § 155.205(c)(1), (c)(2)(i), and (c)(3) to an Exchange call center. HHS will also issue further guidance on language access and such guidance will coordinate our accessibility standards with insurance affordability programs, and across HHS programs, as appropriate, providing more detail regarding literacy levels, language services and access standards.”).

107. *Id.* at 18,336. General standards for Exchange notices also require that the Exchanges must revisit the usability and appropriateness of notices and communication periodically to ensure access. *Id.* at 18,337.

108. 45 C.F.R. § 147.138; *see also* 77 Fed. Reg. at 18,421 (noting that “meaningful access” requires that each Qualified Health Plan’s network “have a sufficient number and geographic distribution of essential community providers, where available, to ensure reasonable and timely access to a broad range of such providers for low-income, medically underserved individuals in the QHP’s service area, in accordance with the Exchange’s network adequacy standards”).

the uninsured were Latino, higher than any other racial or ethnic group in the United States.¹⁰⁹ The uninsured rate for Latinos ranged across states from ten percent or less in Massachusetts and Hawaii to thirty-five percent in twelve states, including eight states where more than forty percent of Latinos were uninsured.¹¹⁰ Low-income working families make up a disproportionately large share of the uninsured—six in ten have at least one full time employee in the household, and over forty percent of the household incomes of the uninsured population falls below the poverty line.¹¹¹

The Affordable Care Act is a direct response to these social phenomena, not specific to Latinos although certainly disproportionately affecting this population. Title I, Section 1501 of the ACA, the “individual mandate” at issue in *National Federation of Independent Business v. Sebelius*,¹¹² requires most¹¹³ individuals and their dependents to have health insurance

109. KAISER COMM’N ON MEDICAID & THE UNINSURED, IMPACT OF THE MEDICAID EXPANSION FOR LOW INCOME HISPANICS ACROSS STATES 1 (2013), available at http://kaiserfamilyfoundation.files.wordpress.com/2013/04/8435_h.pdf. Approximately 32% of Latinos were uninsured in 2009—higher than any other racial or ethnic group. *The Affordable Care Act Helps Latinos*, WHITE HOUSE, available at http://www.whitehouse.gov/sites/default/files/docs/the_aca_helps_latinos_fact_sheet_0.pdf (last visited Oct. 8, 2013). An estimated 9 million Latinos will be newly eligible for coverage under the ACA. *Id.*; see also NAT’L IMM. LAW CTR., IMMIGRANTS AND THE AFFORDABLE CARE ACT, (Mar. 2013), available at <http://www.nilc.org/immigrantsshr.html>; CTRS. FOR DISEASE CONTROL & PREVENTION, *supra* note 101 (discussing undocumented aliens who are excluded from coverage and will remain uninsured after implementation of the ACA). I substitute “Latino” for “Hispanic” throughout this article to recognize the latter as a government-imposed label focused on a group of people with common linguistic roots. Latino, on the other hand, is widely recognized as a pan-ethnic label that emphasizes a shared culture and common history of political, social, and economic subordination experienced in the United States.

110. KAISER COMM’N ON MEDICAID & THE UNINSURED, *supra* note 109, at 1. More than four in eight Latinos (or 35%) were uninsured in twelve states: Alabama, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, and Utah. *Id.*

111. KAISER COMM’N ON MEDICAID & THE UNINSURED, THE HENRY J. KAISER FAMILY FOUNDATION, THE UNINSURED AND THE DIFFERENCE HEALTH INSURANCE MAKES (2012), available at <http://kff.org/uninsured/fact-sheet/the-uninsured-and-the-difference-health-insurance>.

112. Nat’l Fed’n of Indep. Bus. v. Sebelius, 132 S. Ct. 2566, 2573 (2012).

113. See Stephen Zuckerman et al., *Undocumented Immigrants, Left Out of Health Reform, Likely to Continue to Grow as Share of the Uninsured*, 30 HEALTH AFFAIRS 1997, 1999, 2002 (2011) (excluding undocumented immigrants, as only “qualifying” U.S. citizens and legal permanent residents will have access to public insurance under expanded Medicaid/Medicare provisions and private insurance exchanges and arguing that the ACA will not decrease the “uninsured” pool as much as advertised because this group includes a significant number of undocumented immigrants—one in seven of the

that meets the minimum essential coverage requirements.¹¹⁴ Failure to purchase such insurance beginning in January 2014 will result in a tax¹¹⁵ on such individuals.¹¹⁶ The Court in *NFIB* upheld congressional authority to impose a tax for non-compliance as a valid exercise of Congressional taxing power.¹¹⁷ The ACA generally allows premium credits for coverage

uninsured in 2007, up from one in eight in 1999—who will eventually constitute a larger percentage of the uninsured population, unless other policy actions are taken to provide for their coverage or their immigration status is changed); *see also CBO's Analysis of the Major Health Care Legislation Enacted in March 2010: Hearing on H.R. 3950 Before the Subcomm. on Health of the H. Comm. on Energy and Commerce*, 112th Cong. 1 (2011) (statement of Douglas W. Elmendorf, Director, Congressional Budget Office), *available at* <http://www.cbo.gov/sites/default/files/cbofiles/ftpdocs/121xx/doc12119/03-30-healthcarelegislation.pdf> (“About 23 million nonelderly residents will remain uninsured: About one-third of that group will be unauthorized immigrants, who are not eligible to participate in Medicaid or the insurance Exchanges.”).

114. *See* ACA § 1302; 42 U.S.C. § 18022 (2011).

115. Beginning on January 1, 2014, any person without “qualifying health coverage” (covering a list of essential health benefits) must pay a tax penalty, the greater of either a flat rate or a share of household income. KAISER FAMILY FOUND., FOCUS ON HEALTH REFORM: SUMMARY OF THE AFFORDABLE CARE ACT 1 (Apr. 23, 2013), *available at* <http://kaiserfamilyfoundation.files.wordpress.com/2011/04/8061-021.pdf>. The flat rate penalty follows a formula over time. In January 2014, the rate is \$95 for that year, increasing to \$325 in 2015, and \$695 in 2016. *Id.* Thereafter, the flat rate tax penalty increases annually with a cost-of-living adjustment. The maximum annual family flat rate tax is \$2,085, regardless of the size of the family. *Id.* The share of household income, like the flat rate, is incrementally phased in, beginning in January 2014 and starting at 1% of taxable income, then increasing to 2% of taxable income in 2015, and reaching its ceiling at 2.5% of taxable income in 2016 and subsequent years. *Id.*

116. *See* Wendy K. Mariner, *The Affordable Health Care Act and Health Promotion: The Role of Insurance in Defining Responsibility for Health Care Risks and Costs*, 50 DUQ. L. REV. 271, 327 (2012). The “individual mandate” makes it possible for everyone to secure health insurance, including people with preexisting conditions such as diabetes or asthma. *See id.* at 310. The guiding principle is that without such a requirement in place, healthy people would opt out of purchasing insurance and sharing the risk until they needed it, which leads to high premiums and market discrimination for individuals with preexisting conditions. *See id.* at 280 (discussing the foundational principles of shared risk underlying the ACA); *see also* L. Darnell Weeden, *The Commerce Clause Implications of the Individual Mandate Under the Patient Protection and Affordable Care Act*, 26 J.L. & HEALTH 29, 40 (2013) (explaining risk pooling and distribution). The shared risk and pool of resources are meant to reduce premiums and out-of-pocket expenses for health care. *Id.* at 38-39. Exemptions exist for failure to purchase insurance. For example, three exemptions include incarcerated individuals ACA § 1312, 42 U.S.C. § 18032 (2011), those without coverage for less than ninety days (grace period), ACA § 1412, 42 U.S.C. § 18082 (2011), and members of Indian tribes, ACA § 1411, 42 U.S.C. § 18081 (2011).

117. *Nat'l Fed'n of Indep. Bus.*, 132 S. Ct. at 2600.

on the healthcare exchanges for individuals with incomes above the poverty line who do not have access to affordable employer coverage or other public coverage.¹¹⁸

The ACA's Medicaid¹¹⁹ expansion provides coverage for greater numbers of low-income Latinos seeking to access public health care.¹²⁰ Title II, Section 2000 of the ACA requires states to expand Medicaid to nonelderly, non-pregnant individuals with income below 133% of the federal poverty level (\$14,484 for an individual and \$29,726 for a family of four in 2011). The federal government will pay 100% of the costs of the additional coverage for newly eligible individuals for the first three years, and federal support will drop only slightly by 2020 to ninety percent, with the states responsible for the balance.¹²¹ Nine out of ten people without insurance have family incomes below 400% of the poverty line and will

118. January Angeles, *Making Health Care More Affordable*, CTR. ON BUDGET & POL'Y PRIORITIES, available at <http://www.cbpp.org/files/5-19-10health.pdf> (last updated Apr. 3, 2013). The ACA provides "premium tax credits" to assist individuals and families with incomes between 100% and 400% of the federal poverty line (between about \$23,000 to \$94,000 a year for a family of four) who purchase coverage in the newly established health insurance exchanges. *Id.* Individuals are ineligible for premium tax credits if they are eligible for Medicaid or Medicare or if they are eligible for coverage through their employer, unless the coverage does not meet essential health coverage or an employee has to pay more than 9.5% of the employee's income to purchase coverage. *Id.* Documented immigrants with incomes below 100% of the poverty line are eligible for premium credits if they have not lived in the United States for five years and are thus not eligible for Medicaid. *Id.*

119. Medicaid, a federal-state program with joint financing, currently covers more than 50 million low-income individuals. NAT'L CONFERENCE OF STATE LEGISLATURES, STATES IMPLEMENT HEALTH REFORM: MEDICAID AND THE AFFORDABLE CARE ACT (June 2011), available at <http://www.ncsl.org/documents/health/HRMedicaid.pdf> ("Most Medicaid eligibility currently is determined by income and categories of individuals such as children under age nineteen, pregnant women, adults with dependent children, people with disabilities, and the elderly."). Childless adults, who typically are not eligible for Medicaid, make up a large percentage of the nation's uninsured who will become eligible under the ACA. *Id.*

120. *Uncertainty Over States and Medicaid Expansion*, N.Y. TIMES (June 28, 2012), <http://www.nytimes.com/2012/06/29/us/uncertainty-over-whether-states-will-choose-to-expand-medicare.html> (noting the common misconception that Medicaid covers all poor people); see also *Nat'l Fed'n of Indep. Business*, 132 S. Ct. at 2601. A Kaiser Family Foundation study found that a majority of states do not cover non-disabled, non-pregnant adults without dependent children at any income level, and many low-income women only qualify for Medicaid coverage when they are pregnant. See MARTHA HEBERLEIN ET AL., KAISER COMM'N ON MEDICAID & THE UNINSURED, HENRY J. KAISER FAMILY FOUND., PERFORMING UNDER PRESSURE: ANNUAL FINDINGS OF A 50-STATE SURVEY OF ELIGIBILITY, ENROLLMENT, RENEWAL, AND COST-SHARING POLICIES IN MEDICAID AND CHIP, 2011-2012, at 12 (2012).

121. ACA § 2001, 42 U.S.C. § 18001 (2010).

qualify for Medicaid or subsidized coverage under the ACA.¹²² Federal support that states currently receive for their Medicaid programs averages around fifty-seven percent nationally.¹²³ Therefore, Medicaid expansion presents a significant financial incentive for states to opt in. However, to date, twenty-five states have approved Medicaid expansion, four remain undecided, and twenty-one have rejected it.¹²⁴

Latinos have a disproportionately high stake in Medicaid expansion decisions made by a small number of states, namely Florida, California, and Texas, where their absolute numbers are greatest, poverty levels the highest, and projected population growth the most significant. California's decision to opt in will provide public health insurance to 1.4 million low-income, formerly uninsured residents.¹²⁵ Conversely, Texas Governor Rick Perry's decision to reject Medicaid will result in greater spending while providing insurance to fewer people. The nonpartisan RAND Corporation projects Governor Perry and the other governors, including Florida's Governor Rick Scott, who have rejected federal Medicaid expansion, will lose upwards of \$8.4 billion in federal funding through 2016 and leave 3.6 million more people uninsured, all while spending \$1 billion more on public health care in 2016 alone.¹²⁶

2. *Expanding the Scope of Coverage to Include Mental Health Services*

In addition to the insurance expansion initiatives discussed above, the ACA seeks to expand the scope of coverage to include more comprehensive mental health benefits in three areas: (1) strengthening of mental health parity in coverage; (2) inclusion of behavioral health as part of a required slate of ten "essential benefits" that every insurance plan must offer; and (3) prohibiting discrimination in coverage (in both costs and scope) based on pre-existing conditions. First, the move to reinforce mental health parity, or discrepancies between physical and mental health

122. See KAISER COMM'N ON MEDICAID & THE UNINSURED, *supra* note 109.

123. See Social Security Act § 1905(b), 42 U.S.C. § 1396b (2013) (establishing the specific formula used to calculate each state's matching rate, known as the Federal Medical Assistance Percentage ("FMAP") based on a state's per capita income). The FMAPs range from 50% to a high of 74%. KAISER FAMILY FOUNDATION, POLICY BRIEF: MEDICAID AND THE UNINSURED, *available at* <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8352.pdf> (last visited Jan. 12, 2014).

124. KAISER FAMILY FOUND., *supra* note 5.

125. *California to Expand Medicaid*, N.Y. TIMES (June 15, 2013), <http://www.nytimes.com/2013/06/16/health/california-to-expand-medicaid.html>.

126. Pat Garofalo, *GOP Governors Play Politics With Life and Death*, U.S. NEWS & WORLD REP. (June 4, 2013), http://www.usnews.com/opinion/blogs/pat-garofalo/2013/06/04/study-rejecting-obamacare-medicaid-expansion-costs-gop-governors-money_print.html.

coverage, means that the ACA's provisions and recent policy regulations apply to mental as well as primary and specialized health care.¹²⁷ Parity in the ACA relates to insurance coverage in a direct sense but conceptually is also part of the broader move towards equity in quality and access.¹²⁸ The ACA builds upon previous federal directives to address gaps in coverage and disparate treatment of persons with psychosocial disabilities by insurance companies, including the Mental Health Parity Act ("MHPA") of 1996¹²⁹ and the Mental Health Parity and Addiction Equity Act ("MHPAEA") of 2008.¹³⁰

127. DEP'T TREASURY, DEP'T LABOR, DEP'T HEALTH & HUM. SERVS., FINAL RULES UNDER THE PAUL WELLSTONE AND PETE DOMENICI MENTAL HEALTH PARITY AND ADDICTION EQUITY ACT OF 2008, available at <https://s3.amazonaws.com/public-inspection.federalregister.gov/2013-27086.pdf>. Interestingly, President Obama unveiled an initiative to reduce national gun violence specifically, enumerating as an action item, the Department of Health and Human Services' issuance of federal regulations implementing parity protections. WHITE HOUSE, NOW IS THE TIME: THE PRESIDENT'S PLAN TO PROTECT OUR CHILDREN AND OUR COMMUNITIES BY REDUCING GUN VIOLENCE 15, available at http://www.whitehouse.gov/sites/default/files/docs/wh_now_is_the_time_full.pdf (last visited Nov. 17, 2013).

128. See 42 U.S.C. § 300gg-26 (2011). The "Parity" Provision of the ACA, entitled "Applicability of Mental Health Parity," states: "Section 2726 of the Public Health Service Act [PHSA] shall apply to qualified health plans in the same manner and to the same extent as such section applies to health insurance issuers and group health plans." ACA § 1311, 42 U.S.C. § 18031 (2011).

129. Departments of Veterans Affairs and Housing and Urban Development, and Independent Agencies Appropriations, Pub. L. No. 104-204, 110 Stat. 2874 (1996). Congress sought to remedy the shortcomings of the MHPA (e.g., no requirement of parity for substance and alcohol abuse treatment; limits on inpatient days and outpatient visits as well as co-payments) with the promulgation of the MHPAEA—namely, insurance company work-around practices to bypass Congressional intent for parity by structuring different copays, premiums, and deductibles for mental health care, and thus creating disparate treatment for similarly situated individuals. Megan Lagreca, Note, *Treating a Chronic Case of Discrimination: The Ninth Circuit's Prescription for Mental Health Patients' Rights in Harlick v. Blue Shield*, 58 VILL. L. REV. 269, 276 (2013).

130. Under the MHPA and the MHPAEA, group health plans with fifty or more people enrolled must provide "parity in annual and lifetime limits; deductibles, copayments, coinsurance and out-of-pocket expenses; and frequency of treatment, number of visits, days of coverage, and other similar limits on scope or duration of treatment between medical and mental health benefits." James Hodge, Jr. et al., *A Hidden Epidemic: Assessing the Legal Environment Underlying Mental and Behavioral Health Conditions in Emergencies*, 4 ST. LOUIS U. J. HEALTH L. & POL'Y 33, 77-78 (2010). Notably, however, under the MHPAEA, employers do not have to provide mental health and addiction benefits if they do not already and employers are not prohibited from dropping existing mental health benefits. *Id.* State Children's Health Insurance Programs were included in the list of those required to provide parity. *Id.* at 77.

Second, beginning in January 2014, mental health and substance abuse services will be essential components of Medicaid, as well as the new health plans in the state-run insurance exchanges. All qualified plans offered through the health exchanges must cover ten categories of “essential” benefits, which address significant areas of health concerns for the Latino community: (1) ambulatory patient services; (2) emergency services; (3) hospitalization; (4) maternity and newborn care;¹³¹ (5) mental health and substance abuse services, such as behavioral health services;¹³² (6) prescription drugs; (7) rehabilitation and habilitation services; (8) laboratory services; (9) preventive and wellness services and chronic disease management; and (10) pediatric services, such as oral and vision care.¹³³ The ACA requires the Secretary of HHS to periodically review the essential categories and consider “the health care needs of diverse segments of the population, including women, children, persons with disabilities, and other groups.”¹³⁴

Third, with respect to expanding the scope of mental health coverage, the ACA offers protections against discrimination based on pre-existing conditions (such as psychosocial disabilities, diabetes, or asthma). A recent study estimates that one in two non-elderly Americans and more than three in four elderly Americans have a pre-existing condition that pre-ACA would have precluded them from a significant percentage of private

131. According to the Pew Research Institute, Latinas tend to have more children and have them at a younger age than their non-Latina counterparts. PEW RESEARCH, BETWEEN TWO WORLDS: HOW YOUNG LATINOS COME OF AGE IN AMERICA 71 (2013), available at <http://www.pewhispanic.org/2009/12/11/viii-family-fertility-sexual-behaviors-and-attitudes>. More than one-fourth (26%) of Latinas are mothers by the time they reach age nineteen, compared with 22% of blacks, 11% of whites, and 6% of Asians. *Id.* at 9.

132. Studies show that Latinos who are twelve years old and older were more likely than non-Latinos to have needed substance abuse treatment in 2012—9.9% and 9.2%, respectively. See SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., U.S. DEP’T OF HEALTH & HUMAN SERVS., RESULTS FROM THE 2009 NATIONAL SURVEY ON DRUG USE AND HEALTH: MENTAL HEALTH FINDINGS 1 (Dec. 2010), available at <http://www.samhsa.gov/data/NSDUH/2k9NSDUH/MH/2K9MHRResults.pdf>; see also *supra* note 65 and accompanying text.

133. ACA § 1302(b)(1); 42 U.S.C. § 18022 (2011). The Department of Health and Human Services issued its final rule in February 2013 designating the ten categories of essential health benefits required by the online exchanges and plans sold outside of the exchanges, including basic services such as hospitalization and emergency care, mental health, and maternity care. See *HHS Releases Essential Health Benefits Final Rule for Individual, Small Group Plans*, BLOOMBERG BNA (Feb. 25, 2013), <http://www.bna.com/hhs-releases-essential-n17179872551> (“In addition, the plans must cover a minimum of 60% of the actuarial value of covered medical services.”).

134. ACA § 1302(b)(4)(C).

insurance plans.¹³⁵ Finally, the ACA explicitly incorporates the broad protection of civil rights laws to enforce meaningful access to health care. The ACA¹³⁶ extends the protections of Title VI of the Civil Rights Act (race, color, national origin, and gender), Title IX of the Education Amendments of 1972 (gender),¹³⁷ the Age Discrimination in Employment Act of 1975 (age), and Section 504 of the Rehabilitation Act of 1973 (disability) to areas affecting health care access that were not previously protected such as insurance contracts,¹³⁸ tax subsidies, credits to purchase insurance,¹³⁹ and the health exchanges themselves.¹⁴⁰

135. U.S. DEP'T OF HEALTH & HUMAN SERVS., AT RISK: PRE-EXISTING CONDITIONS COULD AFFECT 1 IN 2 AMERICANS (2011), available at <http://aspe.hhs.gov/health/reports/2012/pre-existing/#One>.

136. ACA § 1557, 42 U.S.C. § 18001 (2010). Notably, the ACA omitted the Americans with Disabilities Act (“ADA”) in its final version, while earlier drafts of the legislation included the ADA among other central civil rights statutes.

137. The ACA’s antidiscrimination provisions seek to address the systematic exclusion of women, for example, by “gender rating” (or charging women higher premiums than similarly situated men) by insurers and discrimination based on pre-existing conditions. See DANIELLE GARRETT ET AL., NAT’L WOMEN’S LAW CTR., TURNING TO FAIRNESS: INSURANCE DISCRIMINATION AGAINST WOMEN TODAY AND THE AFFORDABLE CARE ACT 14 (2012), available at http://www.nwlc.org/sites/default/files/pdfs/nwlc_2012_turningtofairness_report.pdf (explaining the ban on gender-rating by insurance companies addressed by the ACA).

138. ACA § 1557 (prohibiting discrimination by “any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under [Title I of the ACA.]”); see also Joel Teitelbaum et al., *Translating Rights into Access: Language Access and the Affordable Care Act*, 38 AM. J.L. & MED. 348, 365 (2012). The ACA broadens the reach of civil rights laws to private entities whose only receipt of federal funding is through an insurance contract. See § 1557.

139. Title I institutes the controversial “health insurance mandate” that was the subject of the Supreme Court decision, *National Federation of Independent Business v. Sebelius*, 132 S. Ct. 2566 (2012). Title I of the ACA establishes health insurance exchanges for both individual consumers and small businesses to purchase health insurance. ACA § 1311, 42 U.S.C. § 18031. Thus, the nondiscrimination requirement reaches health insurers that participate in the exchanges voluntarily or whose customers receive federal assistance (i.e. tax credits or subsidies to purchase insurance). *Id.* § 1557.

140. Regarding the exchanges and the Qualified Health Plans (“QHPs”), the Department of Health and Human Services’ final regulation on non-discrimination prohibits states from “operat[ing] an Exchange in such a way as to discriminate on the basis of race, color, national origin, disability, age, sex, gender identity, or sexual orientation.” Patient Protection and Affordable Care Act; Establishment of Exchanges and Qualified Health Plans; Exchange Standards for Employers, 77 Fed. Reg. 18,309, 18,447 (Mar. 27, 2013) (to be codified at 45 C.F.R. § 155.120). This section provides a floor, and not the ceiling, of protection from discrimination. See *id.* at 18,319.

B. Focusing on the Process of Health Care Delivery: Increasing the Quality of Mental Health Services Provided

The ACA seeks to increase the quality of mental health services provided through two major initiatives: improving the quality of primary care delivery and adopting patient-centered discourse (as suggested in the title of the legislation) to position the help-seeker as the focal point of service delivery.

1. Improving Primary Care Delivery

The ACA invests in the expansion and training of the primary health care workforce to better integrate primary care and behavioral health.¹⁴¹ The focus on primary care is a response to the overspecialization of the medical industry,¹⁴² the shortage of primary care professionals,¹⁴³ and empirical studies recommending the primary care physician as a frontline mental health worker and an integral player in overall health promotion.¹⁴⁴ The ACA creates health homes (also called “medical homes”) at the primary care level for people with qualifying chronic illnesses, including psychosocial disabilities.¹⁴⁵ The primary care physician serves as the patient’s quarterback coordinating specialized care, including mental health and substance abuse support, and ensuring the multilateral exchange of information among all treating health professionals. Remarkably, the statute fails to mention the patient in this information exchange.¹⁴⁶

The focus on primary care has enormous potential to improve the mental

141. See, e.g., ACA § 5405, 42 U.S.C. § 280g-12 (2011); ACA § 5501, 42 U.S.C. § 1395l(x)-(y) (2011) (expanding funding for primary care programs); ACA § 3021, 42 U.S.C. § 1315a (2011) (supporting innovation in the delivery of primary health care such as shifts from fee-for-service to salary based systems).

142. Barbara Starfield et al., *Contribution of Primary Care to Health Systems and Health*, 83 MILBANK Q. 457, 458-59 (2005), available at http://www.commonwealthfund.org/usr_doc/Starfield_Milbank.pdf.

143. Exacerbated by the expansion of health insurance access under the ACA.

144. See, e.g., Starfield et al., *supra* note 142, at 460 (“[H]igher ratios of primary care physicians to population had better health outcomes, including lower rates of all causes of mortality: mortality from heart disease, cancer, or stroke; infant mortality; low birth weight; and poor self-reported health, even after controlling for sociodemographic measures.”).

145. ACA § 2703(h), 42 U.S.C. § 1396w-4(h) (defining qualifying “chronic conditions” and other requirements for participation in health homes). Specifically, the statute requires two qualifying chronic conditions or one chronic condition plus membership in a “high risk group” for a second chronic condition including diabetes, heart disease, asthma, being overweight, substance abuse, or have a mental health disorder. *Id.*

146. *Id.* § 2703(e).

health of Latinos. For example, approximately one-half of all Latinos do not have a regular doctor, compared with only one-fifth of white Americans.¹⁴⁷ When Latinos do report mental health problems to medical professionals, it is usually to a primary care physician as Isabel did in the opening narrative.

2. *Focusing on Patient-Centered Health Care Delivery*

The Affordable Care Act incorporates the rhetoric of “patient-centered care”¹⁴⁸ focused on achieving quality outcomes as well as patient participation in the health care process.¹⁴⁹ The cornerstone of patient-centered care is the quality of the doctor-patient relationship.¹⁵⁰ Sprinkled throughout the ACA are references to “patient-centered care” or “patient-centeredness,” describing the manner in which research should be conducted,¹⁵¹ a criterion for measuring quality outcomes,¹⁵² the appropriate substantive focus of continuing medical education for primary care practitioners,¹⁵³ the types of experimental projects encouraged (and funded)

147. *The Affordable Care Act Helps Latinos*, WHITE HOUSE, available at http://www.whitehouse.gov/sites/default/files/docs/the_aca_helps_latinos_fact_sheet_0.pdf (last visited Oct. 8, 2013).

148. See also MOIRA STEWART ET AL., *PATIENT-CENTERED MEDICINE: TRANSFORMING THE CLINICAL METHOD* (2d ed. 2003). See generally JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 23-25 (2002) (discussing the history of the doctor-patient relationship and philosophical shift to patient-centered care principles); Jo Harkness, *Patient Involvement: A Vital Principle for Patient-Centered Health Care*, 41 *WORLD HOSPS. & HEALTH SERVS.* 12 (2005).

149. See, e.g., John O'Brien, Ctrs. for Medicare and Medicaid, *Behavioral Health: Can Primary Care Meet the Growing Need?* (May 4, 2012), available at <http://www.allhealth.org/briefingmaterials/050412alliancebehavioralhealthtranscripteditd-2297.pdf> (“We are also making sure that as states begin to think about some of the new programs and, frankly, even the existing programs, that we have out there that they really focus on how those programs are more person centered. We’ve talked a lot about that for a long time, but we’ve got a renewed interest in trying to provide some more clarity about what person-centered, self-directed care really means and means to support some of the basic tenets of recovery, resiliency, and successful community integration.”).

150. In 2001, the same year the Surgeon General released its report on disparities in mental health care, the Institute of Medicine’s Committee on Quality of Health Care in America recognized “patient-centeredness” as among its central health care goals—“focus[ing] on the patient’s experience of illness and health care and on the systems that work or fail to work to meet individual patients’ needs.” See *COMM. ON QUALITY OF HEALTH CARE IN AM., INST. OF MED., CROSSING THE QUALITY CHASM: A NEW HEALTH SYSTEM FOR THE 21ST CENTURY* 48 (2001).

151. ACA § 6301, 42 U.S.C. § 1320e (2011).

152. § 3023, 42 U.S.C. § 1395cc-4.

153. § 5301, 42 U.S.C. § 293k.

by the ACA,¹⁵⁴ a component of our national strategy on improving quality health care,¹⁵⁵ and the central goal for the coordination of services in community-based health homes.¹⁵⁶ However, no definition of “patient-centeredness” exists in the 974 pages of the statute. Instead, several sections defer to the Secretary of HHS to give meaning to this term.¹⁵⁷ Other ACA provisions encourage fundamental changes related to health care delivery that facilitate greater patient engagement in the doctor-patient relationship—e.g., streamlined access to patients’ medical records, greater transparency in documenting medical costs, publication of ratings and quality information about institutional providers and health care workers, greater assistance in the selection of insurance (e.g., patient navigators to support enrollment), and management of coverage disputes through “patient-centered” ombudsmen.

C. Focusing on Outcomes: Increasing Improvements in Mental Health

Integral to the ACA’s initiatives to improve efficiency, quality, and prevention is the development of appropriate evaluative assessments. The focus on data collection and evaluation permeates the ACA as a deliberate strategy to reduce health care disparities and improve patient-centered care. The ACA explicitly recognizes the necessity of including qualitative measures of assessment into the evaluative process—e.g., the degree of patient-centered care—as captured by the experience and satisfaction of the patient. In awarding financial support for health care projects, for example, the ACA requires that the Secretary “give priority to the development of quality measures that allow the assessment of—(A) health outcomes and the functional status of patients . . . (E) the safety, effectiveness, patient-centeredness, appropriateness, and timeliness of care; . . . (G) the equity of health services and health disparities across health disparity populations . . . and geographic areas”¹⁵⁸ The ACA also requires the Secretary of HHS to define these criteria and provide regulatory guidance on implementation that remains outstanding.¹⁵⁹

154. § 3021, 42 U.S.C. § 300jj-51.

155. § 3011, 42 U.S.C. § 280j.

156. § 3502, 42 U.S.C. § 256a-1.

157. *See, e.g.*, § 3021; § 3023.

158. § 3013(c)(2), 42 U.S.C. § 299b-31(c)(2).

159. Without a clear definition or guidance as to the contours of “patient-centered care,” the concept continues to be coopted rhetorically by both Democrats and Republicans alike. *See, e.g.*, Maggie Fox, *Not in Kansas: Sebelius Hearing on Obamacare Went Straight to Oz*, NBC NEWS (Oct. 30, 2013), available at <http://www.nbcnews.com/health/analysis-sebelius-hearing-obamacare-website-goes-straight-oz-8C11498853> (statement by House Speaker John Boehner (R-OH): “There is

The initiatives discussed in this Section will generate improvements, and yet the ACA does not (and cannot on its own terms) result in meaningful access for millions of people such as Isabel who are not likely to respond to the fundamental monochromatic delivery of these reforms.

III. TOWARD MEANINGFUL ACCESS: THE LIMITS AND LESSONS OF THE ACA

This section returns to the story of Isabel presented in the introduction of this Article as a lens to show how—and why—the ACA falls short in its ambitious reform agenda discussed in Section II. The shift to patient-centeredness to ensure meaningful access requires more than what the ACA, or any federal health legislation, can provide. How do the reforms outlined above affect Isabel? Under the ACA's access reforms, Isabel and her family are required to purchase or hold health insurance. Perhaps they were previously eligible for public health insurance or, post-ACA's Medicaid expansion, are now eligible. How does the ACA communicate this information to Isabel? Perhaps patient navigators conduct outreach in Spanish and successfully enroll Isabel. She now has access to an insurance plan (public or private) that covers mental health diagnosis and treatment as an essential benefit. Assume that scope of coverage information is communicated to her in Spanish. The threshold reforms have successfully positioned Isabel to use the formal health care system. However, the reforms in health care delivery under the ACA are mostly aspirational because the authority to regulate the practice of medicine falls within the states' police powers.¹⁶⁰

This section draws upon Isabel's story to introduce two broader deficiencies in mental health care delivery: (1) the failure to incorporate the lessons of critical race theory, cultural studies, and disability theory into the substantive and regulatory frameworks governing the practice of health care professionals; and (2) the failure to value and incorporate patient-centered, collaborative decision-making models into regulatory and ethical frameworks governing health care delivery and the health care workforce. This section then introduces proposals for shifting the underlying norms

no way to fix this monstrosity We want to repeal Obamacare and replace it with patient-centered health care.”).

160. States have the authority to impose regulations on the private rights of their citizens in order to protect their citizens' health, safety, and welfare by means of the “plenary police power.” States' authority to regulate the practice of medicine falls within this plenary police power. *See* *Barsky v. Bd. of Regents*, 347 U.S. 442, 449 (1954); *see also* *State v. Gee*, 236 P.2d 1029, 1033 (Ariz. 1951) (explaining that states “[have] the power and duty to control and regulate such professions and practices affecting the public health and welfare”).

that drive health care delivery in the United States. The focus here is on Isabel, the ACA, and framing Isabel's challenges as more problematic theoretical holes in health care delivery that must be addressed in order to improve mental health outcomes.

A. Cultural Collisions, Illness Perception, and Stigma

Critical race theorists offer two central concepts for health law that should inform the construction of institutions and regulatory norms for health care delivery: indeterminacy and social construction. Critical race theory¹⁶¹ holds that the law has no single, neutral truth because all laws are subject to interpretation and filtered through particular experiences and biases. Moreover, the law itself reflects the dominant, white male majority's values, often marginalizing culture and behavioral norms in communities of color.¹⁶² “[R]ace and racism are endemic to the American normative order and a pillar of American institutional and community life. [The] law does not merely reflect and mediate pre-existing racialized social conflicts and relations...[i]nstead [it] constitutes, constructs and produces races and race relations in a way that supports white supremacy.”¹⁶³ The same analysis can be applied to health care institutions and, in particular, mental health, where definitions of “health” and “illness” are largely socially constructed and reflective of majority values.¹⁶⁴

The social model of disability¹⁶⁵ offers an additional critical lens through which to understand mental illness and mental health promotion. Broader social responsibility for creating and exacerbating disability demands a different approach to “health” promotion. Bagenstos clarifies:

161. I recognize that no one strand of “critical race” theory exists, just as there is no single identifiable (and widely accepted) strand of feminism. For a discussion of the evolution of critical theory and the conflicts within that spawned related movements, see Athena Mutua, *The Rise, Development and Future Directions of Critical Race Theory and Related Scholarship*, 84 DENV. U.L. REV. 329, 331-341 (2006).

162. See *supra* Part I.A. and corresponding notes. See generally CRITICAL RACE THEORY: THE KEY WRITINGS THAT FORMED THE MOVEMENT (Kimberle Crenshaw, Neil Gotanda, Gary Peller & Kendall Thomas eds., 1995).

163. *Supra* note 161, at 333 (citations omitted).

164. See *supra* Part I.B.

165. See *supra* Part I.C. (discussing the medical versus social models of disability and the historical construction of mental health and illness).

[T]he disability rights argument is not that disability is entirely a social creation, only that it must be understood as the result of an interaction between biological restrictions and the broader physical and social environment—and that the greater part of the disadvantage attached to “disability” is best addressed through attempts to change the environment.¹⁶⁶

The operative question shifts from what limitations does the individual have to what supports does the individual with psychosocial disabilities need in order to participate equally in society.

1. Cultural Collisions and Illness Perception

Help-seeking behaviors and coping strategies for mental and psychosocial disabilities are influenced, in part, by an individual’s self-perception of symptoms,¹⁶⁷ his or her ability to communicate a particular narrative of his or her illness or pain,¹⁶⁸ and the attitudes and knowledge he or she may have about available supports.¹⁶⁹ Isabel’s story illustrates the

166. Samuel R. Bagenstos, *Subordination, Stigma, and Disability*, 86 VA. L. REV. 397, 430-431 (2000) (citation omitted).

167. One study found that the most salient factors in Latinas’ decision to seek an appointment with a mental health professional are the type of problem, beliefs about the origin of the mental health problem, and having a family member or friend with experience seeking assistance with that or a similar mental health problem. Jennifer Alvidrez, *Ethnic Variations in Mental Health Attitudes and Service Use Among Low-Income African American, Latina and European American Young Women*, 35 COMMUNITY MENTAL HEALTH J. 515, 516-17 (1999). Interestingly, stigma regarding psychosocial problems or preference for using informal means of support (community, religious figures, friends, family) are often also listed, although this particular study found that they were not statistically relevant as predictors of Latina’s utilization of formal mental health services. *Id.* at 522.

168. Areheart, *supra* note 82, at 371.

169. See, e.g., ARTHUR KLEINMAN, *RETHINKING PSYCHIATRY: FROM CULTURAL CATEGORY TO PERSONAL EXPERIENCE* 19-24 (1988) (discussing cross cultural variations in the prevalence and nature of mental health disorders); R. Angel & P. Thoits, *The Impact of Culture on the Cognitive Structure of Illness*, 11 CULTURE, MED. & PSYCHIATRY 465 (1987) (setting forth a theoretical framework for understanding how cultural background influences an individual’s perception of their mental and physical health); L.J. Kirmayer et al., *Symptom Attribution in Cultural Perspective*, 3 CAN. J. PSYCHIATRY 584, 584-95 (1994) (indicating that cultural differences that influence how an individual understands their psychological disorder can affect the pathogenesis, course, clinical presentation, and outcome of the disorder); see also A.I. Hallowell, *Fear and Anxiety as Cultural and Individual Variables in a Primitive Society*, in CROSS-CULTURAL STUDIES OF BEHAVIOR 475 (Ihsan Al-Issa & Wayne Dennis eds., 1970) (“The norm of one culture is a sign of nervous pathology in the other.”); Harriet P. Lefley, *Foreword*, 34 CMTY. MENTAL HEALTH J. 455, 457 (1998) (“[T]he way any illness is experienced is clearly linked to the social context in which the individual lives.”).

disconnect in “illness perception” experienced by Dr. Smith and Isabel.¹⁷⁰ Each has his or her own ideas about the identity, cause, duration, and consequences of Isabel’s challenges. Cultural collisions prevent effective communication beyond linguistic differences.¹⁷¹

To understand the cultural collisions at work in Isabel’s story, it is necessary to step back and look at how various cultures view mental disabilities and how definitions of mental disabilities change with time. While one culture¹⁷² may condemn an “eccentric” mind,¹⁷³ another may venerate that same mind as capable of understanding the supernatural. One’s mental state may be the cause of discrimination or may cause one to be celebrated as a prophet or wise person depending upon cultural norms

170. In health psychology, “illness perception” includes five interrelated components: (1) label or identification—how people label and describe their illness and the symptoms attributable to the illness; (2) causes—ideas about the cause of the illness; (3) timeline—expectations of how long the illness will last (e.g., acute, chronic); (4) consequences—effects and outcomes expected of the illness, and (5) controllability—beliefs about whether the illness is amenable to treatment and/or personal control. See Howard Leventhal et al., *Illness Representations: Theoretical Foundations*, in PERCEPTIONS OF HEALTH AND ILLNESS 26 (Keith J. Petrie & John Weinman eds., 1997); see also Howard Leventhal et al., *The Common-Sense Model of Self-Regulation of Health and Illness*, in THE SELF-REGULATION OF HEALTH AND ILLNESS BEHAVIOR 42, 42-65 (Linda D. Cameron & Howard Leventhal eds., 2003); Howard Leventhal et al., *The Common Sense Representation of Illness Danger*, in CONTRIBUTIONS TO MEDICAL PSYCHOLOGY 18 (S. Rachman ed., 1980); Howard Leventhal et al., *Illness Representations and Coping with Health Threats*, in HANDBOOK OF PSYCHOLOGY AND HEALTH: SOCIAL PSYCHOLOGICAL ASPECTS OF HEALTH 219, 219-52 (Robert J. Gatchel et al., 1982).

171. Language is necessary but not sufficient. For example, in 1973, a study of service utilization in New York for Latinos revealed that language is certainly necessary but insufficient to address the normative tensions at play when Latinos come into contact with U.S. mental health institutions. Marin et al., *supra* at 29-30. Specifically, the study showed that Latinos with schizophrenia were deemed sicker when interviewed in English. *Id.* at 29. The authors offered three hypotheses: (1) the differences were due to raters’ prejudices; (2) the patients underwent change when they spoke English, probably because of the tension, and “gave up;” and (3) the English raters’ frame of reference was not applicable to Latino patients. *Id.* at 29-30. A study published in 1981 comparing separately recorded Spanish-language and English-language interviews found that subjects expressed more symptoms and greater severity during the Spanish interviews. *Id.* at 30.

172. “Culture” in this Article refers to the particular designs and practices of living that are normally transmitted from one generation to another—for example, “familial roles, communication patterns, affective styles, and values regarding personal control, individualism, collectivism, spirituality, and religiosity.” See Hector Betancourt & Steven Regeser López, *The Study of Culture, Ethnicity, and Race in American Psychology*, 48 AM. PSYCHOLOGIST 629, 630 (1993).

173. *Id.*

and historical context.¹⁷⁴ Some cultures treat the behaviors associated with schizophrenia as an illness to be medicated and eradicated, while others respond positively and see such behavior as a blessing of expanded consciousness.¹⁷⁵ Isabel's conception of mental disability collided with that offered by the doctor in the mobile clinic. Isabel understood mental and psychosocial disabilities in its most severe form requiring institutionalization. Anything short of such social isolation was understood as something to be addressed as a private family matter.

Evidence about Latinos' perceptions of mental illness comes from the field of medical anthropology.¹⁷⁶ Mexican American norms of health and illness exist on a continuum¹⁷⁷ without the same distinctions between the physical and mental/spiritual realms pervasive in mainstream American bio-medical practices.¹⁷⁸ This literature describes an array of culturally-determined labels used by Latinos to categorize and make sense of mental and psychosocial disabilities, such as *nervios* (nerves), *fallo mental* (mental deficiency or failure), and *locura* (craziness).¹⁷⁹

174. See *id.* at 635.

175. See *id.*

176. See Leopoldo J. Cabassa et al., "It's Like Being in a Labyrinth": Hispanic Immigrants' Perceptions of Depression and Attitudes Towards Treatments, 9 J. IMMIGRANT HEALTH 1, 13-14 (2007) (indicating that mental health professionals should incorporate Latino patients' perceptions and attitudes into treatment for depression).

177. See, e.g., Ana Castillo, *Brujas and Curanderas: A Lived Spirituality*, in MASSACRE OF THE DREAMERS: ESSAYS ON XICANISMA 151 (1995) (discussing the experiential dynamics of curanderismo and its experience of mind/body and soul/spirit on a continuum).

178. Interestingly, Mexican-American beliefs in the origins of illness themselves reflect a historical collision between indigenous Aztec and Anglo-Spanish knowledge and experience from the biological imbalance to the role of divine punishment. See ROBERT T. TROTTER, JR. & JUAN ANTONIO CHAVIRA, CURANDERISMO: MEXICAN AMERICAN FOLK HEALING 18-19 (1981); see also Maritza M. Tafur et al., *A Review of Curandermismo Healing Practices Among Mexicans and Mexican Americans*, 16 OCCUPATIONAL THERAPY INT'L 82, 84 (2009).

179. See LLOYD H. ROGLER ET AL., TRAPPED: PUERTO RICAN FAMILIES AND SCHIZOPHRENIA 153-54 (3d ed. 1985) (discussing information from medical anthropologists about Latino perceptions of mental disability); Peter J. Guarnaccia et al., *Si Dios Quiere: Hispanic Families' Experiences of Caring for a Seriously Mentally Ill Family Member*, 16 CULTURE, MED. & PSYCHIATRY 187, 193-201 (1992) (examining how an individual's understanding of severe mental disability affects her response to a family member with a severe mental illness); Janis H. Jenkins, *Conception of Schizophrenia as a Problem of Nerves: A Cross-Cultural Comparison of Mexican-Americans and Anglo-Americans*, 26 SOC. SCI. & MED. 1233, 1240 (1988) (finding variations in indigenous conceptions of psychosis that were related to an ethnicity and socioeconomic status).

One of the most widely studied labels popular among Mexicans, Cubans, and Puerto Ricans, in particular, is “nervios” (nerves), an umbrella term used to describe common human emotions such as fear, anxiety, depression, anger, worries, loss of control, and stressful life circumstances—a term used by Isabel to describe her symptoms.¹⁸⁰ “Nervios is often linked to individuals’ etiological conceptualizations of mental health problems that are associated with situational factors, such as romantic problems, school and/or work failure, interpersonal problems, strain in social roles, and death of loved ones.”¹⁸¹ Mainstream psychology most often maps “nervios” onto a diagnosis of depression.¹⁸² Other conditions discussed within the Latino community include “susto”¹⁸³ and “mal de ojo.”¹⁸⁴

180. Cabassa et al., *supra* note 176, at 2; *see also, e.g.*, Peter J. Guarnaccia et al., *The Experience of Ataques de Nervios: Towards an Anthropology of Emotions in Puerto Rico*, 20 CULTURE, MED. & PSYCHIATRY 343, 351 (1996) (discussing the role of social context in the loss of control associated with ataques de nervios); Peter J. Guarnaccia et al., *Toward a Puerto Rican Popular Nosology: Nervios and Ataque de Nervios*, 27 CULT MED PSYCHIATRY 339, 348-49 (2003) (examining different categories of nervios among Puerto Ricans living in Puerto Rico and the United States).

181. Cabassa et al., *supra* note 176, at 2. Interestingly, the conceptualization of causes is highly gendered and class dependent. *Id.* (“Hispanic women, mostly Puerto Ricans and Cubans, identified emotional problems, such as failures of romantic relationships and divorce, as triggers for mental illness, while men attributed mental illness to failure in social roles (e.g., loss of work, failures at school). In the same study, those with higher education and income attributed mental health problems to a medical condition rather than to situational or emotional factors.”).

182. *See* AM. PSYCHIATRIC ASS’N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 356 (4th ed. 2000) [hereinafter DSM-IV-TR]. The DSM-5 does not appear to have made any changes to this diagnostic classification. *See* AM. PSYCHIATRIC ASS’N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 155, 160-68 (5th ed. 2013) [hereinafter DSM-5]. The DSM-5 acknowledges that cultural concepts are relevant but, unlike the prior version of the DSM, no longer endorses the use of the term “culturally-bound” syndrome. Instead, the DSM-5 adopts a view that the term “ignores the fact that clinically important cultural differences often involve explanations or experiences of distress rather than culturally distinctive classifications of symptoms.” *Id.* at 758.

183. *See* DSM-IV-TR, *supra* note 182, at 903. “Susto” translates as “fright” or “loss of the soul.” *See id.* A person may suffer from “susto” if they experience a particularly frightening event which causes the soul to leave the body, resulting in sadness, loss of pleasure, and sickness. Symptoms may include changes in appetite, sleep difficulties, nightmares, headache and stomach aches, sadness, and lack of motivation. *See id.* This somewhat maps onto mainstream psychology’s definitions of trauma or trauma-related illnesses such as post-traumatic stress disorder.

184. *See id.* at 901. This concept of the “evil eye” exists in many cultures. Children are most often thought of as being the targets of and vulnerable to “mal de ojo.” Symptoms include sleep difficulties, restlessness, crying without apparent cause,

Four central values that pervade Latino culture and history require some discussion in order to understand and support Latina mental health: “familismo,” “personalismo,” “respeto,” and “machismo.”¹⁸⁵ Latinos focus on family supports in times of crisis or difficulty. Isabel herself cared for her brother who one could infer suffered from an intellectual or psychosocial disability. Second, the impersonal nature of the doctor’s visit and the lack of investment in learning about Isabel’s background in order to establish a relationship conflicts with the Latino belief in “personalismo”—a focus on personal character and one’s ability to get along well with others. This value also includes distaste for confrontation or conflict even when warranted to protect one’s rights. “Respeto” requires a significant showing of respect for others and demanding a high level of respect in return. This reciprocity is difficult to establish, and takes time. Finally, “machismo” refers to traditional gender roles within the household and within the larger Latino community, with Latinas as caregivers for the family who defer to the male head of the household and male community leaders. Although Isabel knew Dr. Smith dismissed relevant information, he was a man with greater education than she had and thus she did not challenge him directly.

The DSM IV, IV-TR, and now iteration V, all mention the importance of culture in psychiatric diagnosis;¹⁸⁶ yet in practice, there is not much specific guidance available for mental health professionals to incorporate cultural competency into practice. Furthermore, given the intimate link between the DSM classifications and receipt of public benefits, the tension between getting the right diagnosis for benefits eligibility and de-pathologizing difference is front and center. Dr. Smith’s knowledge of Isabel is limited to data points collected by his medical intern, Helena, at intake (such as age, race/ethnicity, address, employment status, and a history of hospitalizations), a brief physical examination of Isabel, and a handful of follow-up questions he asks during her physical examination

diarrhea, vomiting, and fever. *See id.* This appears to map most closely onto “colic.”

185. *See generally* GERARDO MARÍN & BARBARA VANOSS MARÍN, RESEARCH WITH HISPANIC POPULATIONS 11-17 (1991) (describing central Latino values across different racial, ethnic, and national lines as: (a) group oriented, (b) valuing harmonious interpersonal relationships, (c) loyal to family, (d) deferent to authority figures or revered relatives, and (e) valuing traditional gender roles).

186. Most recently, the DSM-5 provides information on the relationship between mental disorders and culture, social, and familial norms and the symptoms, signs, and behaviors that are criteria for diagnosis. AM. PSYCHIATRIC ASS’N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 14 (5th ed. 2013). The DSM-5 includes a separate section on “Cultural Formulation,” which discusses culture and diagnosis. *Id.* at 749-59; *see also* Lewis-Fernández, et al., *Culture and the Anxiety Disorders: Recommendations for DSM-V*, 27 DEPRESSION & ANXIETY 212, 212-29 (2010).

translated by his intern. Dr. Smith has a very specific frame of reference and lens for processing Isabel's challenges. He is trained as a primary care physician. He regularly consults the Diagnostic Statistical Manual ("DSM") for patients he believes are facing mental health issues. In fact, Dr. Smith has a copy of the latest DSM-PC¹⁸⁷ a much shorter, skeletal version for primary care physicians with the list of diagnostic categories and a brief description of each. These diagnostic "crib notes" provide a quick reference for the most common diagnoses, such as anxiety and depression.¹⁸⁸ After reviewing Isabel's intake form, conducting a physical examination and hearing a case summary from his Spanish-proficient medical student, Dr. Smith is confident that Isabel is depressed and suffers from an anxiety disorder.

While Latino idioms such as "nervios" may capture the basic symptoms of hopelessness, sadness, and chronic fatigue used in a DSM classification,¹⁸⁹ the causes of such challenges diverge from the biomedical model of mental and psychosocial disabilities. Latinos view lack of social supports ("sin apoyo"), economic problems (money, job loss), and interpersonal problems as the three main causes of anxiety and depression,¹⁹⁰ often without a biological component.¹⁹¹ All three reflect the

187. AM. PSYCHIATRIC ASS'N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS PRIMARY CARE VERSION (4th ed. 1995); see also R.V. Marino, *DSM-PC: Experiences in Primary Care Practice and Resident Education*, 18 J. DEVELOPMENTAL BEHAV. PEDIATRICS 174, 174-75 (1997); David Pingitore & Randy A. Sansone, *Using DSM-IV Primary Care Version: A Guide to Psychiatric Diagnosis in Primary Care*, 58 AM. FAM. PHYSICIAN 1347, 1347-52 (1998) (offering a comparison of the DSM-IV and DSM-IV-PC, and identifying potential limitations of the DSM-PC); M.L. Wolraich, *Diagnostic and Statistical Manual for Primary Care (DSM-PC) Child and Adolescent Version: Design, Intent, and Hopes for the Future*, 18 J. DEVELOPMENTAL & BEHAV. PEDIATRICS 171, 171-72 (1997).

188. Several other assessments exist to assist physicians in the diagnostic process. For example, self-report measures of specific psychiatric disorders such as the Duke Anxiety-Depression Scale. See George R. Parkerson et al., *Anxiety and Depressive Symptom Identification Using the Duke Health Profile*, 49 J. CLINICAL EPIDEMIOLOGY 85, 85-93 (1996) (comparing the Duke Anxiety-Depression Scale to other measures).

189. Cabassa et al., *supra* note 176, at 2. Depression is when

[a]ll of your problems must have accumulated and [you don't] ask for help in time and things get worse and worse. It is when your problems get all tangled up and you can't find a solution and problems continue accumulating and one feels worthless and discouraged and tired and one can't sleep and you wake up tired without strength to face the day. Everything seems almost impossible to do One feels useless.

Id. at 6.

190. *Id.* at 7.

191. Iran Barrera et al., *Perceptions of Mental Illness Among Mexican-Americans in the Rio Grande Valley*, 22.1 J. ETHNIC & CULTURAL DIVERSITY IN SOC. WORK 1, 3

highly social, situational, and interpersonal understanding of depression in the Latino community. Latinos often attribute the causes of depression to social pressures and life circumstances rather than to internal mechanisms related to biological, genetic, or chemical factors. In one study of Latinas, “depression represented ‘being in a labyrinth’ of interpersonal problems and economic strains, and lacking the emotional support system to help them cope with these difficulties in their everyday life.”¹⁹² Further, depression and anxiety were closely linked with the disintegration of the family as the principal emotional and instrumental support system. Threats to the family through economic stress, domestic violence, social isolation, and immigration represent core causal factors linked to the experience of depression among Latinos.¹⁹³

2. Stigma

Erving Goffman described stigma as a “sign” or a “mark” that designates the individual as “spoiled” and thus less than fully human.¹⁹⁴ Mental and psychosocial disabilities are the most stigmatized of all disabilities.¹⁹⁵ One in four people in the United States have a psychosocial disability and one in two will have one in their lifetime. As prevalent as mental disability is, deeply entrenched stigma and misunderstanding compel many to ignore the rights of persons with mental or psychosocial disabilities.¹⁹⁶ Stigma exacerbates and perpetuates mental disability, operating “as both a cause and a consequence.”¹⁹⁷ Stigma and discrimination are barriers that affect a

(2013) (citing Cabassa et al., *supra* note 176); *see also* Marin et al., *supra* note 97, at 23-37 (discussing a study of beliefs about the cause of mental disability among the elderly and the finding that Latinos were less likely than whites or African Americans to endorse bio-psychosocial causes of depression, and this lower endorsement predicted lower use of mental health services).

192. Cabassa et al., *supra* note 176, at 12.

193. This is linked to the Latino value of familismo.

194. ERVING GOFFMAN, *STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY* 1-40 (1963). Goffman discusses three classes of stigma or stigmatizing conditions: (1) “abominations of the body,” (2) “blemishes of individual character” (such as mental illness), and (3) “tribal identities” (such as race, ethnicity, or religion). *Id.* at 4.

195. Ami C. Janda, *Keeping a Productive Labor Market: Crafting Recognition and Rights for Mentally Ill Workers*, 30 *HAMLIN J. PUB. L. & POL’Y* 403, 411 (2008).

196. The rush to mental health reform in the wake of the 2012 shooting massacres in Aurora and Sandy Hook is running into opposition from mental health advocates who fear the legislation could further stigmatize the mentally ill, while some Latino experts are concerned new tougher laws may prevent some Latinos from even acknowledging mental health needs or finding adequate care.

197. Fred E. Markowitz, *The Effects of Stigma on the Psychological Well-Being and Life Satisfaction of Persons with Mental Illness*, 39 *J. HEALTH & SOC. BEHAV.* 335, 344 (1998) (finding that the impact of stigma on individuals with mental disorders was

person's choice whether or not to seek mental health services. Without the proper psychosocial supports, mental disability may worsen with time and can lead to greater social and economic problems, including unemployment, homelessness, or exclusion from society (i.e. psychiatric hospitalization or imprisonment).

Latino definitions of mental disability are highly correlated with regional history and traditions. A culture of formal mental health care for a spectrum of mental and psychosocial disabilities does not exist in many Latin American and Caribbean countries. Formal diagnoses of mental disabilities are reserved for the most severe cases requiring institutionalization. Depression is one of the least identified psychosocial disabilities requiring professional intervention in Latin America and the Caribbean. The stigma attached to mental disabilities, combined with ethnic minority status in the United States, contributes to Latinos' reluctance to ask for help outside of the immediate family.¹⁹⁸ Furthermore, as a source of shame, stigma has been found to increase caregivers' subjective burden and psychological distress of either struggling with mental disability themselves or caring for a family member with a mental or psychosocial disability.¹⁹⁹

The degree of human agency attributed to producing or maintaining mental or psychosocial disability, particularly depression and anxiety, correlates with the significant stigma attached to mental and psychosocial disabilities—such as depression—among Latinos. This element of the controllability of stigma is important from the perspective of both the stigmatizer as well as the stigmatized person, weighing both on the self-esteem and how the stigmatized person perceives others' reactions to him.²⁰⁰ Stigma exists in broader society,²⁰¹ but makes public or open conversations about mental health and disability particularly difficult when coupled with Latino traditions and values of silence, *familismo*, and community-reliance (or at least containment to the family unit).²⁰² One

correlated with decreased psychological well-being and life satisfaction).

198. Barrio et al., *supra* note 94, at 162.

199. See, e.g., S. Magaña et al., *Psychological Distress Among Latino Family Caregivers of Adults with Schizophrenia: The Role of Burden and Stigma in the Stress-Process Model*, 58 PSYCHIATRIC SERV. 378, 378-84 (2007).

200. John Dovidio et al., *Stigma: Introduction and Overview*, in THE SOCIAL PSYCHOLOGY OF STIGMA 7 (Todd Heatherton et al. ed., 2003).

201. Less than one-third of the estimated 18 million American adults who have a mental or psychosocial disability that affects their day-to-day functioning receive treatment, according to a 2008 government survey. See Sheila Dichoso, *Stigma Haunts Mentally Ill Latinos*, HEALTH.COM (Nov. 15, 2010, 8:36 AM), <http://www.cnn.com/2010/HEALTH/11/15/latinos.health.stigma/index.html>.

202. *Id.* (“When Latinos think of mental illness, they just think one thing: loco.”)

study in California, for example, found high levels of maternal depressive symptoms among low-income Latinas, but only half of these women identified themselves as needing help with depression.²⁰³ In addition, a study of applicants for state benefits found that Latinos were more likely to disclose hallucinations but not to receive a formal diagnosis of psychosis.²⁰⁴

Despite the prevalence of mental and psychosocial disabilities in society and the major scientific advances in understanding and treating many mental disabilities, stigma persists. Studies suggest that society is just as likely to have negative attitudes about people with mental or psychosocial disabilities today as it did fifty years ago.²⁰⁵ Negative attitudes about people with mental or psychosocial disabilities encourage the creation and proliferation of stereotypes, which in turn encourage discrimination. Stereotypes often depict persons with mental or psychosocial disabilities as dangerous and unpredictable, incompetent and childlike, having a defective character, deceptive and unmotivated, or monstrous and demonic.²⁰⁶ Fear and ignorance inspire these stereotypes, which the media continues to exacerbate today.

says Clara Morato, whose son, Rafaello, was diagnosed with bipolar disorder at age 18. “[Latinos] don’t want to be labeled, and they don’t want to be labeled as the family with a relative who’s crazy.”).

203. L.H. Chaudron et al., *Prevalence of Maternal Depressive Symptoms in Low-Income Hispanic Women*, 66 J. CLINICAL PSYCHIATRY 418, 422 (2005).

204. Marin et al., *supra* note 97, at 23-37 (citing a study in Boston that found that almost half of all outpatient Caribbean Latinos reported having hallucinations, but only nine percent of them were diagnosed as having a “thought disorder”).

205. For example, one study concluded that even after Congress promulgated the Americans with Disabilities Act in 1990, “negative attitudes toward persons with mental illness have changed little over the past three decades.” See Marjorie L. Baldwin & Steven C. Marcus, *Perceived and Measured Stigma Among Workers With Serious Mental Illness*, 57 PSYCHIATRIC SERVS. 386, 392 (2006), available at <http://psychservices.psychiatryonline.org/cgi/reprint/57/3/388>.

206. Most recently, James Hamblin of the *Atlantic* reminded us of Allan Hamilton’s 1883 treatise, TYPES OF INSANITY: AN ILLUSTRATED GUIDE TO THE PHYSICAL DIAGNOSIS OF MENTAL DISEASE:

When one walks through the wards of any asylum for the insane, he will immediately be impressed with the repulsiveness of the faces about him, for the general appearance of the insane patient is in no sense prepossessing, and this is especially the case in the female. Women of beauty, as writers upon insanity have written, rapidly lose their good looks with the establishment of mental disease, and the plainness or downright homeliness is the rule among asylum patients, whether of high or low social station.

James Hamblin, *When Looking Insane Got You Committed*, ATLANTIC (Mar. 15, 2013, 12:55 PM), <http://www.theatlantic.com/health/archive/2013/03/when-looking-insane-got-you-committed/273999>.

B. Expertise and Collectivism in Medical Decision-Making

She was an outsider to the county, and to Mrs. G.'s social world. Mrs. G.'s superior sense of the landscape posed a subtle threat to the lawyer's expertise. Sensing this threat, the lawyer steered their strategic "discussion" into the sphere of her own expert knowledge. By limiting the very definition of "strategy" to the manipulation of legal doctrine, she invited Mrs. G. to respond to her questions with silence.²⁰⁷

In 1984, Dr. Jay Katz published what would become one of the most salient critiques of the doctor-patient relationship. He questioned both the utility and effect of the unilateral medical decision-making process premised on the existence of a medical expert sharing knowledge with an idyllic "compliant patient" passively accepting medical decision and prescriptions.²⁰⁸ Instead, he envisioned a dialogue between the doctor and patient rooted in the patient's autonomy and decision-making capacity, information exchange, as well as the therapeutic value of the relationship itself. Accordingly, Katz was "respectful of the law's power to change relationships, yet skeptical that the law's proclaimed attachment for 'self-determination' was matched by a true commitment to bringing about the changes that would improve the physician-patient relationship for both parties."²⁰⁹

The fundamental structure and formalities of the doctor-patient relationship in the United States deter help-seekers such as Isabel by proclaiming Dr. Smith's expertise and unilateral decision-making authority to the exclusion of her voice and knowledge. The structure presumes there is a set of "best" medical solutions to Isabel's problems (similar to determinacy in the law) and Dr. Smith's role is to use his training and superior expertise to unmask the hidden problem, name it, and offer solutions or cures for her ailments. Historically, the medical tradition privileges the doctor's "ability and judgment" to define the patient's best interests without input from the patient herself.²¹⁰ In fact, this notion of "professional autonomy" historically provided an incentive for medical professionals to actively conceal information from their patients with

207. Lucie White, *Subordination, Rhetorical Survival Skills, and Sunday Shoes: Notes on the Hearing of Mrs. G.*, 38 BUFF. L. REV. 1, 47 (1990).

208. See KATZ, *supra* note 148, at 166-69.

209. *Id.* at Foreword, xiii.

210. See Peter Tyson, *The Hippocratic Oath Today*, NOVA (Mar. 27, 2001), <http://www.pbs.org/wgbh/nova/body/hippocratic-oath-today.html#modern> (reproducing the Modern Hippocratic Oath, written in 1964 by Louis Lasagna, Academic Dean of the School of Medicine at Tufts University, and used in many medical schools today).

limited disclosure of present and future predictions.²¹¹ The movement away from traditional medical paternalism—discussed by scholars such as Katz—now encourages greater patient autonomy and collaborative decision-making, but the onerous task of translating these concepts into practice continues.²¹² Perhaps more troubling given the documented inexactitude of medical science in the area of diagnosis of mental disability, courts have “collapse[d] an individual rights claim into an issue of professional judgment [therein] abandon[ing] the task of weighing the constitutional values that may forbid effectuating the professional’s decision. Professionals are neither obligated nor competent to consider these values; this must be the court’s role.”²¹³

Isabel privileges three localized sources of expertise (friends and family, a religious leader, and a community healer) over that of formal health care institutions. Dr. Smith, as does the professional legal colleague in Lucie White’s account of Mrs. G’s Sunday Shoes above, perceives Isabel’s questions as a direct challenge to his training and expertise and, instead of approaching her as a partner in the process or even as someone worthy of his attention, muffles her.

The suppression of Isabel’s voice is problematic for several reasons. First, it obliterates the opportunity to draw upon her expertise, values, and strengths and to contextualize her psychosocial challenges. Even if Dr. Smith’s diagnosis of depression is accurate (despite the inherent subjectivity of the categories and classifications), he has lost an opportunity to draw upon her own resilience and strength²¹⁴ to combat the

211. Rand E. Rosenblatt, *Medicaid Primary Care Case Management, the Doctor-Patient Relationship, and the Politics of Privatization*, 36 CASE W. RES. L. REV. 915, 916-20 (1986) (discussing the history of medical care in the United States).

212. See *id.* at 924 (citing Norman Daniels, *Why Saying No to Patients in the United States Is So Hard: Cost Containment, Justice, and Provider Autonomy*, 314 NEW ENG. J. MED. 1380, 1382 (1986)) (“A plausible contemporary statement of these expanded ethical principles can be found in what Norman Daniels terms the ‘ethic of agency,’ in which physicians’ considerable clinical autonomy is in principle constrained by requirements that ‘clinical decisions be competent, respectful of the patient’s autonomy, respectful of the other rights of the patient (e.g., confidentiality), free from consideration of the physician’s interests, and uninfluenced by judgments about the patient’s worth.’”).

213. Susan Stefan, *Leaving Civil Rights to the “Experts:” From Deference to Abdication Under the Professional Judgment Standard*, 102 YALE L.J. 639, 643 (1992).

214. See Judith A. MacDonnell et al., *Becoming Resilient: Promoting the Mental Health and Well-Being of Immigrant Women in a Canadian Context*, 2012 NURSING RES. & PRAC. 1, 4 (2012) (empowering women as a means of mental health promotion); JAYASREE KALATHIL ET AL., MENTAL HEALTH FOUND., RECOVERY AND RESILIENCE: AFRICAN, AFRICAN-CARIBBEAN AND SOUTH ASIAN WOMEN’S NARRATIVES OF RECOVERING FROM MENTAL DISTRESS 1, 57-71 (2011), available at

environmental stressors active in her life that may be the underlying root causes of her “depression.” In addition, he sends her a clear message about her autonomy, dignity, and role in addressing her own challenges. He reinforces her social and cultural subjugation and vulnerability as a poor, immigrant woman, perhaps further exacerbating her anxiety and stress.

Family provides a critical context for understanding Isabel’s help-seeking behaviors.²¹⁵ Social science literature reflects the importance of *familismo* to the underutilization of formal mental health services.²¹⁶ Interestingly, *familismo* can represent two sides of the same coin, supportive or restrictive, both with the same outcome of underutilization of mental health services. Family can provide natural support networks to collectively assist in problem-solving, or (as discussed above) reflect the source of normative messages regarding stigma associated with seeking formal mental health care in the United States.²¹⁷ Further, Latinos often somatize psychosocial stress, which in part explains their greater use of primary care physicians to resolve manifestations of stress such as stomach aches and nausea, as well as why Isabel reached out to the mobile clinic in the first place.²¹⁸

http://mentalhealth.org.uk/content/assets/PDF/publications/recovery_and_resilience.pdf (addressing the unique issues faced by females within minority groups when faced with mental health problems and collecting stories of recovery and resilience in this group of individuals); Alia Badri et al., *Promoting Darfuri Women’s Psychosocial Health: Developing a War Trauma Counsellor Training Programme Tailored to the Person*, 4 EMPA J. 10, 3 (2013), available at <http://link.springer.com/article/10.1186/1878-5085-4-10> (emphasizing resilience and other modes of psychosocial adaptation).

215. The recent social science literature in this area attributes family as a supportive mechanism to recent immigrants and generations in the United States. While acculturation over time seems to place family as a barrier to service utilization because of normative messaging around stigma of using/engaging the mental health system. See, e.g., *id.* at 244-45.

216. See, e.g., R. Enrique Varela et al., *The Influence of Culture on Anxiety in Latino Youth: A Review*, 12 CLIN. CHILD FAM. PSYCHOL. REV. 219, 219 (2009) (describing a recent study of anxiety and fears among parents of Mexican children in Mexico and Latino children in the United States, who reported more worry and physiological symptoms for their children than Caucasian parents); Golda S. Ginsburg & Wendy K. Silverman, *Phobic and Anxiety Disorders in Hispanic and Caucasian Youth*, 10 J. ANXIETY DISORDERS 517, 525 (1996) (finding that parents of Latino children living in the United States reported higher rates of separation anxiety for their children than parents of non-Latino children living in the United States).

217. The recent social science literature in this area attributes family as a supportive mechanism to recent immigrants and generations in the United States, while acculturation over time seems to place family as a barrier to service utilization because of normative messaging around stigma of using/engaging the mental health system. See, e.g., Chang et al., *supra* note 215, at 236-247.

218. See, e.g., Marin et al., *supra* note 97, at 29 (describing a recent study of parents

Latino culture has consistently been characterized as highly familial, with an interdependent orientation and values that reflect strong commitments to the family collective.²¹⁹ Latinos diagnosed with serious mental disabilities are more likely to live with a family member than their white, non-Latino counterparts; an estimated seventy percent to ninety percent of Latino adults with serious mental illness live with family members.²²⁰ Although many variations in family structures exist, Latino families have been recognized for their extensive social support patterns and kinship networks.²²¹ When it comes to caring for a family member with serious mental disability, women typically are expected to take on the responsibility of providing in-home care and of interfacing with health care institutions (when necessary) on behalf of that family member.²²² For years, many Latino families and communities have been promoting mental health as well as coping and dealing with (severe) mental disability without professional care.

The study of natural support systems and the consideration of how to enhance family-based and community-based caregiving are critical to any discussion of meaningful access to mental health care for Latinos.²²³ Isabel, for example, accessed natural and community supports first. Latinos may be more likely to use informal networks to address psychosocial stressors because of past discriminatory treatment with formal United States health care institutions.²²⁴ The degree of support that exists in the community may also contribute to the treatment options and the resilience of an individual suffering from mental illness or a psychosocial disorder.²²⁵ For example, a series of studies conducted by the World

of Mexican children in Mexico and Latino children in the United States, who reported more worry and physiological symptoms for their children than Caucasian parents).

219. Gordon C. Nagayama Hall, *Psychotherapy Research with Ethnic Minorities: Empirical, Ethical, and Conceptual Issues*, 69 *J. CONSULTING & CLINICAL PSYCHOL.* 502, 506 (2001).

220. Barrio et al., *supra* note 94, at 161.

221. *Id.*

222. *Id.* (“From our research in community-based settings, we observed that mothers, grandmothers, wives, daughters, and sisters occupied the role of the primary caregiver for a loved one with mental illness.”).

223. See, e.g., C. Cox & A. Monk, *Hispanic Culture and Family Care of Alzheimer’s Patients*, 18 *HEALTH & SOC. WORK* 92, 92-100 (1993); S.P. Wallace et al., *Structural Barriers to the Use of Formal In-Home Services by Elderly Latinos*, 49 *J. GERONTOLOGY* 253, 253-64 (1994).

224. For example, Latinos are more likely than Caucasians to perceive the health care system as unfair because of race or ethnicity. See Marin et al., *supra* note 97, at 26.

225. See *CROSS-CULTURAL STUDIES OF BEHAVIOR* 550 (Ihsan Al-Issa & Wayne

Health Organization (“WHO”) found a better outcome for patients with schizophrenia in developing countries than in North America and Europe.²²⁶ One study concluded that fifty-eight percent of the patients in Nigeria and fifty-one percent of the patients in India were in full remission two years after their first treated episode of schizophrenia. In contrast, only six percent of patients in Denmark were reportedly in full remission at follow-ups after two years.²²⁷ In fact, Isabel’s psychosocial challenges themselves may reflect the impact of acculturation and loss of natural supports. Her degree of social embeddedness and connectivity to trusted family and friends has declined since she emigrated to the United States. Lack of connection to others has long been associated with heart disease, depression, risky health behaviors, and a variety of other health outcomes.²²⁸

C. Key Lessons About Health Care Delivery in the United States

Isabel’s story reiterates a familiar lesson in civil rights circles—namely, removing perceived formal barriers to meaningful access is, as Lucie White and Mrs. G have taught us, “not enough in our stratified society to achieve procedural [or substantive] justice, even in the modest sense of enabling all persons to participate in the rituals of their self-government on an equal basis . . . not by overt legal barriers, but by deeply rooted conditions of social inequality.”²²⁹ The ACA offers a promise of equal access to

Dennis eds, Holt, Rinehart and Winston eds., 1970) (“[O]ne of the most important cultural factors which influences or determines the nature of treatment is community attitudes [about mental disability]. Community attitudes towards emotional disorder, especially in cultures outside the West, have been found to be complex Such attitudes may considerably influence what action the patient takes about his disability, and even the content and evolution of his neurotic symptoms. They may impede free communication of his emotional (inner) experiences without the knowledge of which proper diagnosis of his condition is impossible.”).

226. Basic Behavioral Sci. Task Force of the Nat’l Advisory Mental Health Council, *Sociocultural and Environmental Processes*, 51 AM. PSYCHOLOGIST 722, 722 (1996). People diagnosed with schizophrenia “fare far better in developing countries than in North America and Europe.”

227. *Id.*

228. See, e.g., Lisa F. Berkman et al., *From Social Integration to Health: Durkheim in the New Millennium*, 51 SOC. SCI. & MED. 843, 847-53 (2000) (discussing the impact of interpersonal relationships on mental health); SOCIAL CAPITAL AND HEALTH 65 (Ichiro Kawachi et al. eds., 2008) (discussing the impacts of group cohesion on health outcomes); see also DVD: Unnatural Causes, *supra* note 23 (highlighting a community in Pennsylvania of mushroom pickers, Latino immigrants whose health upon arrival was better than that of wealthiest in our country but after five years displayed some of the greatest risks for disease in this community).

229. White, *supra* note 207, at 52.

affordable, quality mental health care, but its provisions fall short of fulfilling this promise for some within linguistically and culturally diverse communities. While its provisions address formal barriers to access, including availability of affordable health insurance, it does not address the underlying roots of disparities in mental health care, namely cultural collisions, bio-medical models of mental disabilities, and what society recognizes as “care.”

The failure to account for normative differences in illness perception across cultures and to diversify health care delivery models has enormous implications for how we think about health outcomes in the United States. Perhaps the most powerful implication is that the current health care delivery system excludes millions of culturally diverse people such as Isabel, perpetuates their exclusion from health care institutions, and denies them the promise of health care. This section introduces three interrelated themes—patient-centered care, expertise, and collective decision-making—and presents choices for state and federal actors to consider in interpreting, defining, and implementing health laws more broadly.

1. Patient-Centered Care and its Progenies

Patient-centered care seeks to bridge the fragmented process in which relevant information is lost, overlooked, or ignored; to avoid wasted resources and lost opportunities such as that of Isabel and Dr. Smith; and to connect help-seekers with timely access to psychosocial supports. Dr. Smith’s role in deterring Isabel from further interaction with the formal health care system cannot be overstated. Isabel faced significant barriers to communicating her needs and goals for the visit, not only because of language or cultural differences but also due to Dr. Smith’s failure to provide patient-centered care. He dismissed Isabel’s role in the process of problem-solving, treated her with disrespect, and lacked compassion. In turn, Dr. Smith lost the opportunity to build a trusting relationship that could potentially overcome the cultural barriers and, at a minimum, open the door to a greater exchange of information. This, in turn, and to the extent warranted and appropriate, could produce a more accurate diagnosis and mutually agreed upon treatment plan (perhaps with a greater likelihood of implementation).

States, as gatekeepers to the medical profession, should consider expanding and refining the importance of patient-centered care in advancing meaningful access. Patient-centered care is the clinical counterpart to client-centered counseling²³⁰ and therapeutic

230. See, e.g., Robert D. Dinerstein, *Client-Centered Counseling: Reappraisal and Refinement*, 32 ARIZ. L. REV. 501, 507 (1990) (“Client-centered counseling may be defined as a legal counseling process designed to foster client-decision-making. Its

jurisprudence,²³¹ both of which situate the law and the lawyer in a supportive role in service of the client's interests and goals. Patient-centeredness (or client-centeredness) refers to the approach, the process, and the goals toward a particular outcome. The patient-centered counseling model, like client-centered counseling in clinical legal education, does not abdicate professional expert opinion. Rather, it enhances its utility by clarifying mutual goals and expectations; exchanging key information and history to contextualize the medical issues presented; identifying natural supports and strengths in the individual, family, and community; and developing practical treatment options tailored to the everyday realities of the patient.

Health professionals engaged in patient-centered practice, particularly when faced with mental health challenges, contribute to the development of a critical consciousness that is transformative for the practitioner, patient, and community.²³² Contextualizing care provides an opportunity for

goal is not only to provide opportunities for clients to make decisions themselves but also to enhance the likelihood that the decisions themselves are truly the client's and not the lawyer's. To accomplish these goals, client-centered counselors must attend to the means they employ in the counseling process, as well as the end of the client-decision-making they attempt to achieve."); DAVID A. BINDER ET AL., *LAWYERS AS COUNSELORS: A CLIENT-CENTERED APPROACH* 2-12 (3d ed. 2012) (discussing the reasons to employ a client-centered approach).

231. See, e.g., DAVID B. WEXLER, *THERAPEUTIC JURISPRUDENCE: THE LAW AS A THERAPEUTIC AGENT* 14 (1990) (examining the "healing" potential or detriment of substantive and procedural elements of our legal system and arguing that "the legal system, itself . . . be examined, and perhaps restructured, to maximize its therapeutic aspects and to minimize its anti-therapeutic aspects"). Therapeutic jurisprudence evolved in the mental health law arena and provides useful insights into the systemic barriers to access that can further exacerbate mental health disorders. The theories associated with therapeutic jurisprudence have extended to other areas of substantive law, including torts. See generally Daniel W. Shuman, *Making the World a Better Place Through Tort Law?: Through the Therapeutic Looking Glass*, 10 N.Y.L. SCH. J. HUM. RTS. 739, 739 (1993).

232. One might imagine incorporation of the Kleinman Explanatory Model, for example, into a patient-centered practice that would allow the person seeking assistance to define and describe her challenge in its specific context. While this name may not map directly onto a diagnostic category, it opens the possibilities for discussion of psychosocial challenges and creates space for collaboration in problem-solving. For example, from the Explanatory Model literature:

What do you call your problem?

What do you think has caused your problem?

Why do you think it started when it did?

What do you think your sickness, issue does to you? How does it work? Why?

How severe is your sickness/issue? Do you think it will have a short or long course?

What kind of treatment do you think you should receive? Why do you think

exploration of the socioeconomic root causes of problems. Breaking down traditional hierarchies and power structures within the doctor-patient relationship through empathy, engaged listening, and respect facilitates a more systematic deconstruction of these power structures outside of the medical office—in the home between spouses or life partners, in the workplace between employers and employees, and in the community at large.²³³ This process of critical reflection, dialogue, and assessment of personal and available community strengths precedes any determination of course of treatment. For the practitioner, engaging in critical reflection also generates a greater connection with the individual and the community. Without this critical reflection, “the context of the situation, that is, oppression, remains unchanged . . . to surmount the system of oppression, [people] must first critically recognize its causes, so that through transforming action they can create a new situation.”²³⁴ In this way, the process itself allows a help-seeker such as Isabel to benefit from increased “psychological empowerment” that includes her perceived control over her life, her critical awareness of her social context, and her political participation in change.²³⁵ This approach challenges the perceived or real powerlessness associated with poverty, chronic environmental stressors, lack of control, and insufficient resources to meet demands—what Leonard

this?

What are the most important results you hope to receive from this treatment?

What are the chief problems your illness/issue has caused you? Your family?

Your community?

What do you fear most about your sickness/illness/issue? Why?

Arthur Kleinman et al., *Culture, Illness, and Care: Clinical Lessons from Anthropological and Cross-Cultural Research*, 88 ANNALS INTERNAL MED. 251, 256 (1978).

233. See, e.g., Dinerstein, *supra* note 231, at 523 (“Clients empowered in their relationship with their lawyer might carry over that sense of power to their relationship with bureaucracies and other power structures. Furthermore, if client-centered counseling values the client’s individual experience by providing an outlet for its expansion within the lawyer-client relationship, clients could be expected to have more opportunities to assert themselves authentically within whatever system they are challenging (or being challenged by) by being able to insist to their lawyers that their perspective gets heard.”).

234. PAOLO FREIRE, *PEDAGOGY OF THE OPPRESSED* 31-32 (Myra Bergman trans., Continuum Int’l Publ’g Group, 3d ed. 2005) (1970).

235. See, e.g., Peterson et al., *Measuring the Interpersonal Component of Psychological Empowerment: Confirmatory Factor Analysis of the Sociopolitical Control Scale*, 38 AM. J. CMTY. PSYCHOL. 287, 287-97 (2006); see also JULIAN RAPPAPORT ET AL., *STUDIES IN EMPOWERMENT: STEPS TOWARD UNDERSTANDING AND ACTION 1-7* (1984) (defining “empowerment” as the enabling process through which individuals or communities take control over their lives and environments).

Syme has called the absence of “control over destiny.”²³⁶ As individuals and communities become more empowered and better able to engage in collective problem-solving, key health and social indicators (as currently defined by the public health community) may reflect these changes with declining rates of alcoholism, divorce, and suicide.

i. Policy Proposal: Expanding the Doctrine of Informed Consent

State tort reform, particularly focused on medical malpractice and expanded duties of informed consent,²³⁷ can transform the ACA’s patient-centered aspirations²³⁸ into meaningful access. Paternalistic state medical malpractice laws and related jurisprudence historically have emphasized medical or therapeutic providers’ autonomy and limited patient rights when faced with profession-friendly (and peer-related) standards of “competent care.”²³⁹ Medical ethics evolved as physicians increasingly saw “patient-centeredness” as a central component of their standard of care, not solely on moral grounds but also for efficiency reasons. The patient holds key information necessary for effective treatment and is best positioned to assess the impact of diagnosis and the likelihood that she will pursue a particular recommended course of treatment. The legal doctrine of informed medical consent developed in the 1950s as courts likewise “acknowledge[d] the reality of choices within medical decision-making and expand[ed] the concept of physician fidelity to mean helping the patient make the crucial decisions.”²⁴⁰ Informed consent laws vary by state and

236. S. Leonard Syme, *Social Determinants of Health: The Community as an Empowered Partner*, 1 PREVENTING CHRONIC DISEASE 1, 3 (2004).

237. See *Tarasoff v. Regents of the Univ. of Cal.*, 551 P.2d 334, 346 (Cal. 1976) (holding therapists’ have a duty of reasonable care to warn an individual who their patient indicates might have an intent to cause bodily harm, and that this duty can be discharged by notifying law enforcement, warning the individual, or taking other reasonable steps); AM. PSYCHOLOGICAL ASS’N (“APA”), APA’S ETHICAL PRINCIPLES OF PSYCHOLOGISTS AND CODE OF CONDUCT, available at <http://www.apa.org/ethics/code/index.aspx> (permitting a psychologist to disclose confidential information about a patient without the patient’s consent when doing so is necessary to “protect the client/patient, psychologist, or others from harm”).

238. See *supra* Part III.

239. See M. Gregg Bloche, *Beyond Autonomy: Coercion and Morality in Clinical Relationships*, 6 HEALTH MATRIX 229, 247 (1996) (discussing informed consent in the mental health context).

240. Rosenblatt, *supra* note 212, at 928 (discussing the doctor-patient relationship). See also *Canterbury v. Spence*, 464 F.2d 772, 787 (D.C. Cir. 1972) (adopting the “reasonable person” standard for informed consent); *Cobbs v. Grant*, 502 P.2d 1, 10 (Cal. 1972) (defining the standard of informed consent as “a duty of reasonable disclosure of the available choices with respect to proposed therapy and of the dangers inherently and potentially involved in each”); *Chamberlain v. Giampapa*, 210 F.3d 154,

govern the scope of disclosure that physicians (and, in some states, nurses) must give patients about undertaking medical care generally, diagnostic tests, or treatment options.²⁴¹

A more robust, patient-centered approach to informed consent, for example, considers Isabel's ability to access the medical information, the quality of the information provided, and the extent of Dr. Smith's cultural due diligence and fact-finding before formulating a diagnosis and recommendations regarding treatment. Studies suggest significant cost-efficacy and improved quality of health care to patients.²⁴² Should there be a heightened responsibility for medical practitioners to conduct cultural due diligence in a post-ACA world where meaningful access matters? Is there a cause of action for negligence against Dr. Smith or a breach of his ethical responsibilities in the realm of informed consent? What legal and non-legal remedies might be available?

161 (3d Cir. 2000) (requiring all "material" information to be disclosed to the patient).

241. Valid informed consent requires the information given be understood by the patient; that she has an opportunity to consider the information presented and ask questions; and, ultimately, that the patient makes a decision in her best interests. For example, in New York, the provider must disclose the "reasonably foreseeable" risks, benefits, and alternatives of a procedure or course of treatment. N.Y. PUB HEALTH LAW §2805(d)(1) (McKinney 2013) ("Lack of informed consent means the failure of the person providing the professional treatment or diagnosis to disclose to the patient such alternatives thereto and the reasonably foreseeable risks and benefits involved as a reasonable medical, dental or podiatric practitioner under similar circumstances would have disclosed, in a manner permitting the patient to make a knowledgeable evaluation."). This standard, however, does not apply to emergency health care. N.Y. PUB HEALTH LAW §2805(d)(2) (McKinney 2013) ("The right of action to recover for medical, dental, or podiatric malpractice based on a lack of informed consent is limited to those cases involving either (a) non-emergency treatment, procedure or surgery, or (b) a diagnostic procedure which involved invasion or disruption of the integrity of the body."). See generally INFORMED CONSENT, AMA CODE OF MED. ETHICS E-8.08, AM. MED. ASS'N, available at <http://www.ama-assn.org/ama1/pub/upload/mm/PolicyFinder/policyfiles/HnE/E-8.08.HTM> (discussing a doctor's obligation to obtain informed consent from their patients).

242. Ravishankar Jayadevappa et al., *Patient Centered Care—A Conceptual Model and Review of the State of the Art*, 4 OPEN HEALTH SERVS. & POL'Y J. 15, 18 (2011) (positing that patient-centered care can improve outcomes); Moira Stewart et al., *The Impact of Patient-Centered Care on Outcomes*, 49 J. FAM. PRAC. 9 (2000) (documenting the benefits of patient-centered health care); MARCI NIELSEN ET AL., PATIENT-CENTERED PRIMARY CARE COLLABORATIVE, BENEFITS OF IMPLEMENTING THE PRIMARY CARE PATIENT-CENTERED MEDICAL HOME: A REVIEW OF COST & QUALITY RESULTS (2012), available at <http://www.healthtransformation.ohio.gov/LinkClick.aspx?fileticket=CPQoPjxO47Q%3D&tabid=114> (indicating that patient-centered care can save health care dollars and improve outcomes).

2. Redefining Expertise and Collaborative Decision-Making

The idealized version of primary health care envisions a kindly gentleman—black tote bag in hand visiting his patient’s home, admonishing the patient for his or her naiveté, and offering a prescription with the proverbial “take two and call me in the morning.”²⁴³

Our health care delivery model is flawed. The transformative and therapeutic power of medicine lies in its ability to share freely information and resources with the greatest numbers. However, the U.S. health care model is built around the expertise of a few highly trained and specialized professionals. The increasing demand for health care services and community supports requires a critical look at of the foundations of medical expertise.²⁴⁴ More than 64 million people currently live in geographic areas that have been designated as having a shortage of primary-care health professionals,²⁴⁵ and others live in smaller areas with health professional shortages more broadly.²⁴⁶ As discussed earlier, the shortage of health professionals in the mental health arena is even more pronounced.²⁴⁷

These systemic limitations derive, in part, from this notion of protecting the professional market and expertise, but also from a limited view of the end goal. The ACA reflects Congressional aspirations for greater equity

243. Tine Hansen-Turton et al., *Nurse-Practitioners in Primary Care*, 82 TEMP. L. REV. 1235, 1236 (2010).

244. The federal Health Resources and Services Administration (“HRSA”) recently reported that at least 55 million Americans live in areas with an inadequate supply of primary care doctors, mostly in rural areas or low-income communities. Health Res. & Servs. Admin., *Shortage Designation: Health Professional Shortage Areas & Medically Underserved Areas/Populations*, U.S. DEP’T HEALTH & HUM. SERVS., <http://www.hrsa.gov/shortage> (last visited Oct. 8, 2013). Massachusetts has the most primary care doctors per capita while Mississippi has the fewest. CTR. FOR WORKFORCE STUDIES, 2011 STATE PHYSICIAN WORKFORCE DATA BOOK 6 (Nov. 2011), available at <https://www.aamc.org/download/263512/data>.

245. As characterized and recognized by the Department of Health and Human Services. See *Primary Medical Care HPSA Designation Criteria*, U.S. DEP’T HEALTH & HUM. SERV., http://bhpr.hrsa.gov/shortage/hpsas/designationcriteria/primarycarehpsa_criteria.html (last visited Oct. 8, 2013) (providing the criteria used to determine whether a geographic area qualifies as having a shortage of primary care providers). In the area of primary health care, the Health Resources and Services Administration (“HRSA”) estimates the United States would need more than 7,500 additional providers to meet the target ratio of one primary care practitioner for every 3,500 residents. See Health Res. & Servs. Admin., *supra* note 245.

246. Kathleen Sebelius, Sec’y, U.S. Dep’t of Health & Human Servs., Message from the Secretary, available at <http://www.hhs.gov/secretary/about/goal5.html> (last visited Oct. 8, 2013).

247. See *supra* Part I.A.

and quality of care, defined narrowly as entry into the formal health care system. While insufficient to transform health care delivery, the ACA does open the door to the possibility of deconstructing traditional hierarchies and power allocation within the medical profession itself (most notably between doctors and nurses) as well as between formal health care workers, natural healers, and community supports. Moreover, the ACA enables task-shifting to lay persons, such as community health workers, to meet the growing demands for culturally competent health care.²⁴⁸

i. Policy Proposal: Task Shifting and Expanded Scopes of Practice

First, although nurse practitioners have assumed an increasingly visible (and reimbursable)²⁴⁹ role in primary health care delivery since the 1970s, their independence and decision-making authority remain inconsistent across jurisdictions, particularly in their medication prescription privileges for psychotropic medication.²⁵⁰ The ACA offers additional funding for advanced practice nurse education, nurse practitioner-led demonstration projects, and loan programs for nurses to pursue advanced nursing degrees, in an effort to expand the health care workforce.²⁵¹ States can capitalize upon these programs and continue to support the expanded scope of practice for nurse practitioners to meet the shortage of primary health care

248. The debate about expanded scope of practice for non-physicians must also include a discussion of quality or perceived inequities, particularly for the most marginalized groups who are positioned to receive services from non-doctors. *State Practice Environments*, AM. ASS'N OF NURSE PRACTITIONERS, <http://www.aanp.org/component/content/article/75-legislation-regulation/state-practice-environment> (last visited Oct. 8, 2013) (providing a link to the nurse practice act in every state); see also Mary O. Munding et al., *Primary Care Outcomes in Patients Treated by Nurse Practitioners or Physicians A Randomized Trial*, 283 JAMA 59, 64 (2000) (finding in the ambulatory care setting no significant difference in the health status of patients treated by a nurse practitioner compared to those treated by a physician after six months).

249. For example, 40% of Medicaid managed care companies now recognize nurse practitioners as independent health care providers. See Hansen-Turton et al., *supra* note 244, at 1237.

250. For example, all states as well as the District of Columbia authorize nurse practitioners or other enumerated categories of nursing professionals (e.g., psychiatric nurse practitioners, clinical nurse specialists (psychiatric), certified nurse anesthetists and certified nurse midwives) to prescribe medications, including psychotropic medications, with certain conditions. Ron Honberg & Joel Miller, *Prescribing Privileges Task Force Report and Recommendations to the NAMI Board of Directors*, NAT'L ALLIANCE ON MENTAL ILLNESS (Dec. 2002), http://www.nami.org/template.cfm?section=policy_research_institute&Template=/ContentManagement/ContentDisplay.cfm&ContentID=4937.

251. Hansen-Turton et al., *supra* note 244, at 1237; see also Public Health Service Act § 8111, 42 U.S.C. § 296(j) (2013).

workers,²⁵² often the only point of contact with formal health care institutions for individuals such as Isabel from culturally and linguistically diverse communities.

Second, states should consider ways to collaborate with existing informal community natural helpers and traditional healers, who, as Isabel's story shows, are recognized community sources of support and collaborative problem-solving.²⁵³ Potential roles for community workers can be divided into two categories—lay workers as the health care providers or lay workers as connectors. The lay worker as the provider of mental health services could include mental health screenings, recommended diagnoses, and counseling, closer to the task-shifting that has occurred between physicians and nurse practitioners. The lay worker as a connector could include strengthening the medical profession's ties with the community through greater engagement in cultural competency training for medical students and continuing medical education; public education in the community about the role and opportunities presented by engaging with the formal medical community; and transfer of health literacy to communities—e.g., how to recognize signs of depression. As the trusted lay health worker “vouches” for the utility of the formal mental health care system, there is greater acceptance of the benefits of mental health care and decreased stigmatization associated with accessing services. For example, Kenya has experimented with task-shifting and using the lay person as both connector and provider of services.²⁵⁴ The Africa Mental Health Foundation trained faith and traditional healers, community-based health workers, and health facility personnel to perform basic psychiatric tasks, such as identifying symptoms, diagnosing conditions, and most importantly, referring patients to formal mental health services if necessary. Results indicate an increase in overall utilization of mental health services as well as an increase in self-referrals, perhaps indicative of reduced stigma, “increased community sensitization, and awareness and

252. For example, Nevada Republican Governor Brian Sandoval signed legislation in June 2013 that affords nurse practitioners with at least two years of experience the opportunity to establish an independent practice with the same scope of practice and services as primary care physicians. See A.B. 170, 77th Leg. Reg. Sess. (Nev. 2013).

253. Eva J. Salber, *The Lay Advisor as a Community Health Resource*, 3 J. HEALTH POL., POL'Y & L. 469, 471 (1979) (“These lay helpers make ideal first contact persons in that they can screen problems and refer persons to appropriate resources, but they go beyond that role in allaying anxiety and giving comfort, counsel, and support so that people are strengthened and able to cope better.”).

254. George Okore, *Traditional Healers Key to Kenya Healthcare Delivery*, AFR. NEWS (Feb. 19, 2013), http://www.africanews.com/site/Traditional_healers_key_to_Kenya_healthcare_delivery/list_messages/42912.

mobilization by the informal health workers.”²⁵⁵

In Ghana, where the number of traditional healers far outnumbers Western-trained doctors, the first stop for many sick people is a natural healer, such as the *curandera* in Isabel’s story. In 2000, Ghana ushered in legislation officially recognizing traditional healers and seeking to integrate them into the formal health care sector on the condition that traditional healers belong to a recognized professional association for safety and regulation.²⁵⁶ To enter these professional associations, healers needed the approval of a local administrator and a traditional chief. The referral and engagement process is a two-way street and has resulted in both quantitative and qualitative improvements (greater numbers of people seeking care as well as improved satisfaction with services). Health status has improved as well as the mutual respect between Western-trained doctors and traditional healers,²⁵⁷ and the ability of help-seekers to avoid exchanging cultural traditions and autonomy for receipt of services.²⁵⁸

The ACA opens a space for formal integration of a well-known community resource for Latinos known as the *promotora de salud* (“community health worker”). Through the funding of community health workers (“CHW”), the ACA provides an opportunity to address the provision of culturally relevant mental health services for Latinas and their families. The ACA formalizes the position of the CHW as a valued member of the health care team.²⁵⁹ While there has been some discussion about the broad utility of CHWs in increasing outreach, education, and access to primary health care in the United States, there has been little attention to its transformative potential in the mental health arena. The *promotoras*, as the community health workers in Ghana and Kenya, are uniquely positioned to address stigma and bridge the relationship between formal health care institutions and the underutilized strengths and support networks available within communities. In considering task-shifting and expanding the scope of practice laws for non-physicians, states should revisit restrictions on confidentiality within the doctor-patient relationship to allow family members or trusted community members to participate in

255. *Id.*

256. Alexandra Zavis, *Doctors in Ghana Working with Traditional Healers*, ASSOCIATED PRESS (May 1, 2000), <http://www.histarch.illinois.edu/harper/ghanadoctor.html>.

257. One Western-trained doctor noted: “It has opened my eyes. . . . I looked at Western health care as the ultimate way, but when we talk to the traditional health care providers, we find there are a lot of things we can learn from them.” *Id.*

258. For example, one CARE spokeswoman noted in reference to the traditional healers: “These people have unparalleled access. That is what we are tapping into.” *Id.*

259. See ACA Pub. L. No. 111-148, § 5313, 124 Stat. 119 (2010).

the process of collaborative decision-making.

CONCLUSION

Meaningful access to mental health care is not simply a change in form but a change in both legal and medical culture. Individuals, medical and legal professionals, families, and communities should realign to share both risk and knowledge in furtherance of performance. The power that flows from this type of social organization is not the power to impose outcomes but to generate ideas and a universe of possibilities producing greater efficiency and supporting empowerment, autonomy, and dignity. The collateral consequences of such a system will shift organizing legal principles. Medical and legal professionals who think about health promotion and social equity with the different lenses discussed in this Article can make meaningful contributions to improving mental health outcomes and fulfilling the broader transformative potential of the Affordable Care Act to deconstruct deeply entrenched institutional biases.