Lambda Legal
making the case for equality

September 30, 2013

U.S. Department of Health and Human Services
Office for Civil Rights
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201
Attn: 1557 RFI (RIN 0945-AA02 & 0945-ZA01)

**Re: Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities**

Lambda Legal appreciates the opportunity to respond to the request of the Department of Health and Human Services (HHS) for information regarding discrimination in health programs, services, and activities and implementation of Section 1557 of the Patient Protection and Affordable Care Act (ACA). We thank HHS for its commitment to ensuring that all people receive affordable and high quality health care and are especially grateful for the work HHS has done to increase access to care for lesbian, gay, bisexual, and transgender (LGBT) people and those living with HIV. Lambda Legal is the oldest and largest national legal organization dedicated to achieving full recognition of the civil rights of LGBT people and those living with HIV through impact litigation, policy advocacy, and public education. We are especially eager to comment on Section 1557 because discrimination based on gender identity, gender expression, sexual orientation, and HIV status are serious problems in our health care system. Lambda Legal has made these problems a primary focus of its work spanning the last four decades and believes enforcement of Section 1557 can reduce this discrimination significantly, with important corresponding improvements in health quality for these populations.

Section 1557 of the ACA provides that an individual shall not be excluded from participation in, denied the benefits of, or be subject to discrimination under any health program or activity, any part of which is receiving federal financial assistance, or under any program or activity established by the ACA on the basis of race, sex (including gender identity and non-conformity with sex stereotypes), disability, or age. The ACA will expand access to quality care for many thousands of currently uninsured and underinsured LGBT and HIV-positive people (1) by creating access to insurance for individuals who have been precluded due to lack of recognition of their family relationships, (2) by eliminating insurance practices that have limited or precluded access to care for people living with chronic conditions, and (3) by forbidding other discriminatory practices and helping to reduce stigma that limit access and reduce quality of care for these vulnerable populations. Because the health disparities affecting LGBT and HIV-positive people are pervasive and long-standing, it is essential that HHS issue guidance making clear that the protections and remedies provided for by Section 1557 are broad, meaningful, and enforceable.

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With Section 1557's mandate in mind, we ask that HHS consider the following key points in response to the issue areas identified in the RFI, which are addressed more fully in the following pages:

(1) LGBT people experience persistent health disparities due to discrimination based on gender identity and sexual orientation, which often are compounded by discrimination based on race, age, disability including HIV, immigration status, limited English proficiency, poverty, and other factors.

(2) LGBT persons perceived as more gender non-conforming tend to experience more discrimination, with transgender individuals facing the most extreme disrespect, refusals of insurance and medical care, and even physical abuse in medical settings. It is time to treat gender dysphoria like other medical conditions and end the discriminatory exclusion of medically indicated care.

(3) The prohibition against sex discrimination in covered health programs, activities and facilities necessarily includes discrimination based on sexual orientation both because sexual orientation is a relational term based on one's sex and because the stigmatizing of same-sex relationships is a function of gender stereotypes.

(4) Health professionals engage in improper discrimination when they provide or refer LGBT persons for aversion therapy to "cure" gender non-conforming behavior, including same-sex attraction. These practices have damaging effects and are repudiated by settled medical consensus and the laws of some states. For health professionals providing care to youth and their families, non-discriminatory practice requires support for acceptance of LGBT youth by other family members, not pressure on LGBT youth to change, because rejection and pressure to change undermine the health of LGBT youth and the relationships on which they depend.

(5) People living with HIV need effective enforcement of Section 1557 to challenge discriminatory insurance plans, discriminatory application of benefit plan rules, and persistent HIV-related stigma and discrimination by providers and health care facilities.

(6) The quality of medical care provided to patients who are, or are perceived to be, LGBT and/or HIV-positive must not be compromised due to the anti-LGBT religious views of either individual health professionals or religiously affiliated organizations providing health services pursuant to state medical licensure and any amount of federal funding.

(7) Harms of discrimination include delay and outright denials of care by insurers and medical providers, as well as lack of care due to avoidance of medical settings prompted by past discrimination. The harms of discrimination also include the mental and physical harms of stigma perpetuated by health professionals and others in health care settings who make those environments hostile for LGBT people and those with HIV.

(8) Appropriate language support is essential for limited English proficient (LEP) LGBT and HIV-positive patients because reliance on either family members or others lacking in cultural competence causes withholding of information essential for quality health care. LEP patients who are socially and/or financially dependent upon family members may be even more fearful than others that disclosure of their HIV or LGBT status, or any health needs related to such status, may cause family rejection.

(9) Where legitimate health needs justify limiting or segregating programs, activities or facilities by sex, individuals must be permitted to participate according to their gender identity.

(10) Information technology can permit increased consistency of health care for LGBT and HIV-positive individuals who are homeless or in transient living situations such as foster care. Confidentiality protections within electronic health records remain important due to persistent stigma concerning a minority sexual orientation and status as transgender or HIV positive.

(11) The established correlation between stigma and longstanding health disparities affecting LGBT people and those with HIV underscore the need for effective enforcement of the anti-discrimination mandate of Section 1557 through the full range of remedies including a private right of action. The fact that protections against discrimination on these grounds remain incomplete and confusing in related federal and state civil rights laws further reinforces this need.

## UNDERSTANDING THE CURRENT LANDSCAPE

### 1. Examples of Discrimination

In 2010, Lambda Legal conducted the first-ever national survey to examine the refusals of care and other barriers to health care confronting LGBT people and those living with HIV: WHEN HEALTH CARE ISN'T CARING.[1] Of the nearly 5,000 respondents, more than half reported that they have experienced at least one of the following types of discrimination in care:

- Health care providers refusing to touch them or using excessive precautions;
- Health care providers using harsh or abusive language;
- Health care providers being physically rough or abusive;
- Health care providers blaming them for their health status.[2]

Almost 56 percent of lesbian, gay, or bisexual (LGB) respondents had at least one of these experiences; 70 percent of transgender and gender-nonconforming respondents had one or more of these experiences; and almost 63 percent of respondents living with HIV experienced one or more of these types of discrimination in health care.[3] Almost 8 percent of LGB respondents reporting having been denied needed care because of their sexual orientation,[4] and 19 percent of respondents living with HIV

[1] LAMBDA LEGAL, WHEN HEALTH CARE ISN'T CARING: SURVEY ON DISCRIMINATION AGAINST LGBT PEOPLE AND PEOPLE LIVING WITH HIV (2010), http://data.lambdalegal.org/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf.

[2] *Id.* at 5, 9-10.

[3] *Id.*

[4] *Id.* at 5, 10.

reported being denied care because of their HIV status.[5] The picture was even more disturbing for transgender and gender-nonconforming respondents, who reported the highest rates of being refused care (nearly 27 percent), being subjected to harsh language (nearly 21 percent), and even being abused physically (nearly 8 percent).[6]

Respondents of color and low-income respondents reported much higher rates of hostile treatment and denials of care. Nearly half of low-income respondents living with HIV reported that medical personnel refused to touch them, while the overall rate among those with HIV was nearly 36 percent. [7] And while transgender respondents as a whole reported a care-refusal rate of almost 27 percent, low-income transgender respondents reported a rate of nearly 33 percent. [8] People of color living with HIV and LGB people of color were at least twice as likely as whites to report experiencing physically rough or abusive treatment by medical professionals.[9]

The WHEN HEALTH CARE ISN'T CARING report explains the context of this study and its recommendations. Accompanying the report are eight supplements providing excerpts of the personal testimonies submitted by study participants and presenting findings about particular subgroups; these supplements are:

- Lesbian, Gay, Bisexual and Transgender (LGBT) People and People Living with HIV Speak Out[10]
- LGBT People of Color and People of Color Living with HIV[11]
- LGBT Women[12]
- LGBT Older Adults and Older Adults Living with HIV[13]
- LGBT Immigrants and Immigrants Living with HIV[14]
- Transgender and Gender-nonconforming People[15]

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[5] *Id.*

[6] *Id.* at 10-11.

[7] *Id.* at 11.

[8] *Id.*

[9] *Id.* at 12.

[10] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-people-and-people-living-with-hiv-speak-out.pdf. Examples from these testimonies are provided in the following sections.

[11] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-people-of-color.pdf.

[12] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-women.pdf.

[13] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-older-adults-and-older-adults-living-with-hiv.pdf.

[14] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-immigrants-and-immigrants-living-with-hiv.pdf.

[15] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_transgender-and-gender-

- People Living with HIV[16]
- Low-Income or Uninsured LGBT People and People Living with HIV[17]

The study results showing that LGBT and HIV-positive people who also are people of color, older, immigrants and/or low income experience much more discrimination in health care settings, with correspondingly compromised health outcomes, than people who do not experience such compounding of vulnerabilities reinforce that Section 1557 must be implemented and enforced effectively. What follows to assist HHS in pursuing those goals is information responding to the issue areas listed in the RFI drawn from Lambda Legal's survey, from years of experience litigating discrimination cases and developing health policy recommendations, and from other sources. First is information about discrimination based on gender identity, then sex discrimination against LGB people, and then discrimination against people living with HIV.

## A. Examples of Discrimination Based On Gender Identity, Gender Stereotypes and Sexual Orientation That Should Be Prevented By Enforcement Of Section 1557

### 1. Gender Identity Discrimination In Health Insurance and Services Undermines the Health of Many Transgender Americans

While LGBT people as a whole are insured at lower percentages than the overall American population,[18] transgender individuals are uninsured and underinsured to an ever greater extent and frequently are denied coverage and access to quality care specifically because of their transgender status.[19] This section addresses three problem areas for transgender patients: (a) biased treatment and discriminatory refusals of care unrelated to the person's gender and transition; (b) refusals of sex-specific care; and (c) refusals of transition-related care.

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nonconforming-people.pdf.

[16] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_people-living-with-hiv.pdf.

[17] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_low-income-or-uninsured.pdf.

[18] *See* Laura F. Redman, *Outing the Invisible Poor: Why Economic Justice and Access to Health Care is an LGBT Issue*, 17 GEO. J. POVERTY L. & POL'Y 451, 453-54 (2010) (compiling statistics). *See also* THE INST. OF MED., THE HEALTH OF LESBIAN, GAY, BISEXUAL AND TRANSGENDER PEOPLE: BUILDING A FOUNDATION FOR BETTER UNDERSTANDING 25-88 (2011) (IOM Report), http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx.

[19] Redman, *Outing the Invisible Poor*, *supra* note 18, at 453-54; TRANSGENDER LAW CENTER, *Transgender Health and the Law: Identifying and Fighting Health Care Discrimination* (July 2004) ("Many transgender people have their applications for health insurance denied when they disclose their transgender status or transition-related medical history (such as hormone level tests) to a potential insurer."), http://transgenderlawcenter.org/pdf/Health%20Law%20fact%20sheet.pdf.

**(a) Discriminatory treatment of transgender people needing care unrelated to their gender identity**

It now is well-established that transgender people face very significant barriers to appropriate, high-quality health care. From verbal abuse and humiliation to refusals of care, our health care system presents a minefield of discrimination for transgender people. The end result is a broad disengagement from the health care system that results in dire health outcomes for transgender people as a group. Rather than enduring degradation and poor treatment, a great many transgender people simply do without care. As a result of this disengagement, treatable medical conditions routinely become emergency problems with compromised outcomes, a common situation in communities with suboptimal access to care.[20]

Following Lambda Legal's 2009 survey, the National Transgender Discrimination Survey (the NTDS) of 2011 again revealed widespread disparities in transgender health care. Of over 6,000 transgender individuals who responded, 19 percent reported having been refused health care due to their transgender or gender non-conforming status. In addition, 28 percent had postponed necessary health care when sick or injured and 33 percent had delayed or not sought preventive care because of prior health care discrimination based on their transgender status.[21]

Even when health care is not refused, the biased behavior toward transgender people by hospital staff – including physicians, nurses, allied health professionals, admitting and registration personnel, and security officers – creates a negative experience that discourages future care seeking. As reported in the community surveys, such behavior too often has included:

- Laughter, pointing, joking, taunting, mockery, slurs, and a wide variety of negative comments;
- Violations of confidentiality, regardless of HIPAA;
- Use of improper names and/or pronouns for patients;
- Exceptionally long waits for care;
- Inappropriate questions and/or exams, including needless viewing of genitals;
- Prohibitions of restroom use;
- Inappropriate room assignments;
- Malpractice and even physical assault.[22]

Discrimination by individual practitioners is more than a matter of requesting different care providers; it can be a matter of life and death. For example:

- Emergency medical services workers in the District of Columbia were called to the scene of a car accident in which Tyra Hunter, a transgender woman, had been seriously injured.

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[20] *See* IOM REPORT, *supra* note 18, at 25-88.

[21] JAIME M. GRANT, PH.D., ET. AL., INJUSTICE AT EVERY TURN: A REPORT OF THE NATIONAL TRANSGENDER DISCRIMINATION SURVEY, 76 (2011) (Grant, NTDS), http://transequality.org/PDFs/NTDS_Report.pdf.

[22] *Id*. at 74 (finding that 28% of survey participants reported having been subjected to verbal harassment in medical settings and 2% were victims of violence in doctors' offices).

As Tyra lay unconscious, the EMS professionals discovered she had male genitalia and stopped providing emergency treatment to her, instead starting to laugh and make derogatory comments. Tyra died as a result of their withholding of medical care.[23]

- Author Leslie Feinberg was denied treatment for endocarditis, a heart condition, at an emergency room when sie was revealed to be transgendered.[24]
- Nakoa Nelson, a transgender man in Hawaii, had a near-fatal allergic reaction to eating a cookie after church. His partner drove him to the closest fire station for help, but when the EMS workers realized he was transgender they refused to treat him. Although Nakoa did find a doctor nearby who gave him steroid shots to help him breathe, the doctor said Nakoa could have died because of the delay.[25]

The three trangender individuals just described have a medical condition classified in the current edition of the Diagnostic and Statistical Manual (DSMV) as "gender dysphoria," previously having been classified as "gender identity disorder."[26] As is discussed in (c) below, it remains common for health insurance policies categorically to exclude coverage for gender dysphoria and for some medical care providers to refuse to treat gender dysphoria.[27] Separate from the propriety of these exclusions and refusals to treat, however, is the fact that such exclusions and refusals often are used to deny all treatment to transgender individuals, improperly correlating an individual's GD diagnosis with unrelated care needed on a routine or even emergency basis.[28] One assessment of the field concluded that "[s]ome insurance companies maintain a broad definition of 'transition-related' [issues] and create false

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[23] *See* Sue Anne Pressley, *Realizing, Fulfilling 'Who They Are': D.C. Slayings Help Galvanize Transgender Community's Push for Acceptance*, WASHINGTON POST (Nov. 29, 2003); Gay & Lesbian Activists Alliance of Washington D.C., *District Settles Hunter Lawsuit for $1.75 Million* (Aug. 10, 2000), http://www.glaa.org/archive/2000/tyrasettlement0810.shtml.

[24] *See* Leslie Feinberg, TRANS LIBERATION 2 (1998) (recounting the experience) (sie is hir preferred gender pronoun).

[25] LAMBDA LEGAL, TRANSGENDER RIGHTS TOOLKIT: TRANSITION-RELATED HEALTH CARE (Feb. 7, 2013) (Transition-Related Health Care), http://www.lambdalegal.org/publications/trt_overcoming-health-care-discrimination.

[26] American Psychiatric Association, *Gender Dysphoria* (2013), http://www.dsm5.org/Documents/Gender%20Dysphoria%20Fact%20Sheet.pdf.

[27] Transgender Law Center, *Transgender Health and the Law*, *supra* note 19, at 2-3. *See also* Lambda Legal, TRANSITION-RELATED HEALTH CARE, *supra* note 25.

[28] *See* Kari E. Hong, *Categorical Exclusions: Exploring Legal Responses to Health Care Discrimination Against Transsexuals*, 11 COLUM. J. GENDER & L. 88, 92 (2002) ("[M]any insurers liberally apply the SRS exclusion clauses to deny transsexuals coverage for non-transition related, medically necessary conditions such as back pain, intestinal cysts, and even cancer, under the rationale that any medical care a transsexual needs is an excludable transsexual-related condition."); Transgender Law Center, *Transgender Health and the Law: Identifying and Fighting Health Care Discrimination*, at 2 (July 2004) ("Insurers justify these exclusions by stating that your current medical problem is somehow related to your transition. For example, the insurer might argue (often times without any proof) that liver damage or blood clotting results from hormone therapy."), http://transgenderlawcenter.org/issues/health/transgender-health-and-the-law-identifying-and-fighting-health-care-discrimination.

connections between illness and transition," stretching to categorize any possible medical need as transition related.[29] For example, in one documented case, an insurance company refused to pay the costs of treating a transgender man's broken arm, wrongfully asserting that even that medical need was related to his transgender status.[30]

The physical and emotional harms of such discrimination are significant for transgender people and those who do not conform to gender stereotypes. Consequently, many simply avoid medical care, even when they are sick or injured, sometimes with severe health consequences.[31]

**(b) Denial of sex-specific medical care**

Transgender people are regularly denied sex-specific healthcare. This includes preventative care such as prostate cancer screenings and gynecological exams, as well as treatment for sex-specific illness. This is partly a function of health insurance coding according to which sex-specific care is coded with a specific gender marker.[32] When an individual needs care associated with a sex different from the gender coding of that person's records, the coding does not match and often neither the insurer nor the care provider adjusts and responds appropriately to the patient's needs. Insurers frequently claim that their systems simply cannot recognize two genders for one client, even though trans people commonly require health care needed by both sexes. As one commentator explains, "The law assumes that sex is binary: an individual can be a man or a woman, but not both or neither."[33] As a result, transgender people are routinely denied insurance coverage for medically necessary care that does not correspond with the gender recorded in their documents.

Discrimination in accessing sex-specific care extends beyond preventative care. Transgender people are also routinely denied health insurance coverage for treatment of sex-specific cancers and other diseases. [34] Health insurers have used even a *suspicion* of transgender status to deny coverage of medical

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[29] J. Denise Diskin, *Taking it the Bank: Actualizing Health Care Equality for San Francisco's Transgender City and County Employees*, 5 HASTINGS RACE & POVERTY L.J. 129, 137 (2008).

[30] Transgender Law Center, *Recommendations for Transgender Health Care*, http://www.transgenderlaw.org/resources/tlchealth.htm#_ftnref2.

[31] *See* Grant, NTDS, *supra* note 21, at 76 (reporting that 28% of transgender and gender non-conforming respondents, and 42% of transgender men, postpone or avoid medical treatment when they are sick or injured because they anticipate disrespect and discrimination).

[32] See KELLAN BAKER & JEFF KREHELY, CHANGING THE GAME: WHAT HEALTH CARE REFORM MEANS FOR LESBIAN, GAY, BISEXUAL, AND TRANSGENDER AMERICANS 19 (2011) (hereinafter CHANGING THE GAME) at 18-19 ("Some health services, such as gynecological exams and certain cancer screenings, are traditionally 'gendered,' meaning that health insurers routinely refuse to cover these services for anyone whose gender marker on their insurance documents does not match their physical anatomy."), http://www.americanprogress.org/issues/lgbt/report/2011/03/29/9200/changing-the-game/.

[33] Liza Khan, Note: *Transgender Health at the Crossroads: Legal Norms, Insurance Markets, and the Threat of Healthcare Reform*, 11 YALE J. HEALTH POL'Y L. & ETHICS 375, 377 (2011).

[34] *See* TRANSGENDER LAW CENTER, *Transgender Health*, *supra* note 19, at 2-3 ("Female-to-male transgender people, in particular, may have difficulty obtaining gynecological services or treatment for gynecological cancers.").

care. In one documented example, a lesbian who had breast cancer in one breast decided, along with her physician, to have both breasts removed to protect against recurrence. Her insurance company "worried that the second breast was 'elective surgery' and that, if they paid for that, it would be setting a precedent for covering elective transsexual surgery."[35] Another sadly famous example is the refusal by twenty-seven physicians to treat Robert Eads, a transgender man, for his ovarian cancer, a disease which initially was treatable but from which he eventually died.[36]

Given the role of gender markers for securing coverage for sex-specific care, and the frequency with which transgender people cannot secure insurance at all once their transgender status is known, some who are insured are apprehensive about changing the gender marker on their insurance policy after they have transitioned.[37] Others have attempted to change the gender marker on their health insurance records after fully transitioning but have been denied the ability to do so by their insurer. [38] Still others have discovered that their gender marker has been changed without their knowledge by doctors or nurses acting on their own.[39]

This problem is solvable. For example, the Centers for Medicare and Medicaid Services (CMS) has created additional billing codes to prevent transgender patients from being inappropriately denied coverage when the gender marker on the insurance record is not the gender typically associated with a certain medical treatment.[40] To accomplish this adjustment broadly, it may simply require direction from HHS, pursuant to Section 1557, that programs, activities and services receiving federal funding must take the same step.

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[35] Khan, *supra* note 33, at 388 n.67, quoting Judith Butler, *Undiagnosing Gender*, TRANSGENDER RIGHTS 283 (Paisley Currah et al. eds., 2006) (internal quotation marks omitted).

[36] SOUTHERN COMFORT (Kate Davis, director and producer, 2001), as discussed in Elvis Mitchell, FILM REVIEW; *Genders That Shift, but Friends Firm as Bedrock*, NY TIMES (Feb. 21, 2001), *available at* http://movies.nytimes.com/movie/review?res=9B01E5DC1639F932A15751C0A9679C8B63. *See also* Kari E. Hong, *Categorical Exclusions: Exploring Legal Responses to Health Care Discrimination Against Transsexuals*, 11 COLUM. J. GENDER & L. 88, 98-99 (2002) ("Female-to-male transsexuals report doctors who will not administer gynecological care.").

[37] *See* Grant, NTDS, *supra* note 19, at 151 (only 39% of people who are fully transitioned have changed the gender marker on their health insurance records).

[38] *Id.*

[39] *Id.* ("Once the nurses or doctor find out I have a penis, they start referring to me as a male and often change my [recorded] gender status to male, which messes up Medicare and Medicaid paying for my hospitalization.").

[40] *See* Medicare Claims Processing Manual, *Billing Requirements for Special Services*, §240 (Special Instructions for Services with a Gender/Procedure Conflict), http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/clm104c32.pdf; *Instructions Regarding Processing Claims Rejecting for Gender/Procedure Conflict*, http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNMattersArticles/downloads/MM6638.pdf. *See also* National Center for Transgender Equality, *Medicare Benefits and Transgender People* (Aug. 2011), http://transequality.org/Resources/MedicareBenefitsAndTransPeople_Aug2011_FINAL.pdf.

In addition to gender-related insurance problems, many transgender individuals are especially uneasy about having their bodies examined in the context of sex-specific care.[41] Most doctors are not trained about the needs of transgender individuals, including how to address patients' anxieties about how they will be received.[42] Combining the uneasiness of both doctors and patients with the propensity of insurance companies to deny coverage for sex-specific care, many transgender individuals forego basic, preventative health care. This contributes to worsened health outcomes, including higher HIV and other sexually transmitted infection rates among transgender and gender non-conforming populations.[43]

**(c) Denial of coverage for gender transition-related health care**

Leading authorities in the medical and policy communities, including the American Medical Association and American Psychological Association, have recognized the medical necessity of hormone therapy and sex reassignment surgery (SRS) for some patients with gender dysphoria.[44] Yet, the historical exclusions of transition-related medical care such as hormone therapy and SRS remain in the health insurance contracts of the majority of public and private insurance companies – preventing coverage even when a doctor confirms the treatment is medically necessary for a patient.[45] Such

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[41] Harvey J. Makadon et al., THE FENWAY GUIDE TO LESBIAN, GAY, BISEXUAL AND TRANSGENDER HEALTH 354 (2007) ("It is common for transgender men to refuse breast and pelvic exams, and for transgender women to refuse testicular and prostate exams.").

[42] The ACA does promote cultural competency standards for health care providers that have the potential to alleviate the problem. *See* CHANGING THE GAME, *supra* note 32, at 12.

[43] *See* NTDS, *supra* note 19, at 80 (reporting HIV infection rate among respondents four times greater than the infection rate of the general population). An additional 8% of respondents reported not knowing their HIV status. *Id.*

[44] For a full compilation of professional organizations' statements in support of access to care for transgender patients, *see* LAMBDA LEGAL, PROFESSIONAL ORGANIZATION STATEMENTS SUPPORTING TRANSGENDER PEOPLE IN HEALTH CARE, http://www.lambdalegal.org/publications/fs_professional-org-statements-supporting-trans-health. *See also, e.g.*, AM. PSYCHOLOGICAL ASS'N, COUNCIL OF REPRESENTATIVES, TRANSGENDER, GENDER IDENTITY, & GENDER EXPRESSION NON-DISCRIMINATION (Aug. 2008), http://www.apa.org/about/policy/transgender.aspx ("APA recognizes the efficacy, benefit and medical necessity of gender transition treatments for appropriately evaluated individuals and calls upon public and private insurers to cover these medically necessary treatments"); AM. MED. ASS'N, RESOLUTION 122: REMOVING FINANCIAL BARRIERS TO CARE FOR TRANSGENDER PATIENTS (June 2008), http://www.ama-assn.org/resources/doc/hod/a08resolutions.pdf ("Resolved, That our American Medical Association support public and private health insurance coverage for treatment of gender identity disorder as recommended by the patient's physician."); AM. MED. ASS'N H.D., RESOLUTION 122 (A-08): REMOVING FINANCIAL BARRIERS TO CARE FOR TRANSGENDER PATIENTS (June 2008), http://www.tgender.net/taw/ama_resolutions.pdf ("Whereas, An established body of medical research demonstrates the effectiveness and medical necessity of mental health care, hormone therapy and sex reassignment surgery as forms of therapeutic treatment for many people diagnosed with GID; and . . . Health experts in GID . . . have rejected the myth that such treatments are 'cosmetic' or 'experimental' and have recognized that these treatments can provide safe and effective treatment for a serious health condition . . . therefore be it . . . Resolved, That the AMA oppose categorical exclusions of coverage for treatment of gender identity disorder when prescribed by a physician . . . .").

[45] *See* LAMBDA LEGAL, TRANSGENDER RIGHTS TOOLKIT: TRANSITION-RELATED HEALTH CARE, *supra* note 25;

exclusions sometimes also deny coverage for visits to monitor hormone replacement therapy, to receive ongoing transition assistance, and for psychological counseling. These exclusions generally were based on the now-outdated misconception that the treatments are experimental or cosmetic. Despite today's settled medical consensus that this care is medically necessary for some patients, the exclusions remain common.[46]

The unjust harms of such exclusions have been recognized in an ever lengthening list of court decisions addressing the medical needs of prisoners and recognizing that it is wrongful discrimination to treat the medical needs of this minority differently from the needs of others.[47] Although this is not a new

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Kari E. Hong, *Categorical Exclusions*, *supra* note 28, at p. 92 ("Despite the DSM-IV diagnosis, the medical community's internationally endorsed treatment, and the documented side effects of leaving gender dysphoria untreated, most public and private insurers explicitly exclude coverage for sex-reassignment surgery [SRS]."); Pooja Gehi & Gabriel Arkles, *Unraveling Injustice: Race and Class Impact of Medicaid Exclusions of Transition-Related Health Care for Transgender People*, 4 SEXUALITY RESEARCH & SOC. POL'Y: J. OF NSRC 7, 9 (2007) ("Twenty-four states explicitly exclude coverage for transition-related health care by [state Medicaid] regulation. . . . In those states that do not have an explicit exclusion, coverage for transition-related care may still be denied based on interpretation and application of a more general exclusion, such as for so-called experimental or cosmetic treatments.").

[46] *See* THE WORLD PROFESSIONAL ASSOCIATION FOR TRANSGENDER HEALTH, STANDARDS OF CARE FOR THE HEALTH OF TRANSSEXUAL, TRANSGENDER, AND GENDER NONCONFORMING PEOPLE (7th ed.), http://www.wpath.org/documents/Standards%20of%20Care%20V7%20-%202011%20WPATH.pdf (providing clinical guidance for health professionals to assist transgender patients with primary care, gynecologic and urologic care, reproductive options, voice and communication therapy, mental health services, and hormonal and surgical treatments); THE ENDOCRINE SOCIETY, ENDOCRINE TREATMENT OF TRANSSEXUAL PERSONS: AN ENDOCRINE SOCIETY CLINICAL PRACTICE GUIDELINE (2009), https://www.endocrine.org/~/media/endosociety/Files/Publications/Clinical%20Practice%20Guidelines/Endocrine-Treatment-of-Transsexual-Persons.pdf.

[47] In harmony with the medical consensus, there now is a consensus among federal courts that gender dysphoria constitutes a serious medical condition and that failures to provide prisoners adequate treatment can violate the Eighth Amendment. *See De'lonta v. Johnson*, 708 F.3d 520, 523 & 525 (4th Cir. 2013) (reversing dismissal of Eighth Amendment claim where non-surgical treatment failed to address gender dysphoria and plaintiff sought SRS, "an accepted, effective, medically indicated treatment for GID"); *Battista v. Clarke*, 645 F.3d 449, 451-52 (1st Cir. 2011) (affirming finding of Eighth Amendment violation where evidence showed plaintiff would likely engage in genital self-surgery and requiring provision of hormone therapy); *Fields v. Smith*, 653 F.3d 550, 555-56 (7th Cir. 2011) (holding that a state law barring hormone therapy and SRS for transgender prisoners violated the Eighth Amendment); *White v. Farrier*, 849 F.2d 322, 325 (8th Cir. 1988) (recognizing that gender dysphoria presents a serious medical need); *O'Donnabhain v. Comm'r of Internal Revenue*, 134 T.C. 34, 62 (U.S. Tax Ct. 2010) ("Seven of the U.S. Courts of Appeals that have considered the question have concluded that severe GID or transsexualism constitutes a 'serious medical need' for purposes of the Eighth Amendment"). In fact, even the U.S. Supreme Court has recognized gender dysphoria as a serious medical condition, noting its inclusion (as "transsexualism") in the Diagnostic and Statistical Manual and the AMA's Encyclopedia of Medicine. *See Farmer v. Brennan*, 511 U.S. 825, 829 (1994). For more information about why it can be unconstitutional for prisons to categorically deny medically necessary care for gender dysphoria, see discussion of Lambda Legal's litigation of *Fields v. Smith* at http://www.lambdalegal.org/in-court/cases/fields-v-smith.

view among those attentive to the issue,[48] public discussion about the medical needs of transgender people has only recently become amplified. As a result, many more people understand not only that SRS is not cosmetic but also that gender dysphoria does not abate spontaneously and cannot be treated by changing the person's gender identity through psychotherapy.

Although public support is growing rapidly, individuals with gender dysphoria who lack access to appropriate medical care may become desperate and engage in harmful self-treatment, as the following examples illustrate:

- Emilie of Boise, Idaho reported to Lambda Legal's health care survey: "I am a post-operative trans woman who began my gender transition in 2004. After talking about transitioning with my family MD, she agreed to continue her medical relationship with me. … she referred me to a local endocrinologist who could perform blood work and recommend a hormone replacement regime. When I called the endocrinologist to set up an appointment, I was told by the secretary, "We don't treat people like you." I called the two other local endocrinologists and was told the exact same thing. My psychologist told me that some of her clients experienced the same … She told me that they just don't want trans people in their waiting rooms because they might make other customers feel uncomfortable, or they simply have a moral objection to trans people. Endocrinologists like this relegate people like me to self-medicate, which can be dangerous to our health. Hormones are easily available over the Internet without a prescription."[49]
- Mia Rosati, a transgender prisoner in state custody in California, is appealing the dismissal of her complaint against the California Department of Corrections. Her request for an individualized assessment of whether genital surgery is medically necessary in her case to address her extreme gender dysphoria has been refused based on the prison's policy, followed by the physician's assistant who processed her request, that SRS is cosmetic. In desperation, Ms. Rosati has attempted self-surgery on at least three occasions. Lambda Legal represents Ms. Rosati in her appeal to the Ninth Circuit.[50]

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[48] *See, e.g., J.D. v. Lackner*, 80 Cal. App. 3d 90, 95 (1978) ("We do not believe, by the wildest stretch of the imagination, that [sex reassignment] surgery can reasonably and logically be characterized as cosmetic.").

[49] Lambda Legal, Lesbian, Gay, Bisexual and Transgender (LGBT) People and People Living with HIV Speak Out, *supra* note 10.

[50] *Rosati v. Igbinoso*, Case No. 1:12-cv-01213-RRB , 2013 U.S. Dist. LEXIS 60247, at * 4 fn. 14, *5 (E.D. Cal. April 26, 2013) **(**"Prior to being imprisoned Rosati partially emasculated himself by surgically removing his testicles" and he "reported a history of prior self-mutilation attempts and … felt having male genitalia while having other physical characteristics of a woman, had led to significant psychological distress"), *on appeal*, Ninth Circuit Court of Appeals Case No. 13-15984. *Compare Battista v. Clarke*, 645 F.3d 449, 451-52 (1st Cir. 2011) (evidence showed plaintiff Battista needed hormone therapy and likely would engage in genital self-surgery if denied proper medical treatment).

## 2. LGB People Experience Improper Sex Discrimination In Health Care

### (a) Sex discrimination against LGB people includes bias based on same-sex attraction and relationships as well as bias based on non-conformity with gender stereotypes

Director of the Office of Civil Rights, Leon Rodriguez, confirmed last year that Section 1557's sex discrimination prohibition includes discrimination based on gender identity or failure to conform to stereotypical notions of masculinity or femininity, as well as to sexual harassment and other forms of sex discrimination regardless of the actual or perceived sexual orientation or gender identity of the individuals involved. [51] Some uncertainty has remained about whether the sex discrimination prohibition covers the particular subset of sex discrimination that is based on sexual orientation. HHS already has included explicit prohibitions against sexual orientation discrimination in final rules for health insurance Exchanges, QHPs, and the EHB.[52] The present RFI does not, however, explicitly enumerate sexual orientation discrimination among the forms of sex discrimination identified for illustration purposes. It thus will be helpful to have this subset of protection made explicit in the implementing regulations for Section 1557.

There should be little doubt, however, that the sex discrimination prohibition necessarily includes discrimination based on sexual orientation, for at least two reasons. First, sexual orientation is a relational term based expressly on one's sex; it cannot be understood without sex-based references and distinctions. Second, the stigmatizing of same-sex relationships is a function of gender stereotypes and perceptions that persons who engage in such relationships are improperly disregarding their proper, gender-based roles.

Concerning the first framing of the point, many scholars and numerous courts, in contexts concerning both family relationships and discrimination against individuals, have considered this a straightforward analysis.[53] A person's sexual orientation is a function of the person's own sex in relation

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[51] Letter of Leon Rodriguez to Maya Rupert dated July 12, 2012 (OCR Transaction Number: 12-000800).

[52] *See, e.g.*, 45 C.F.R. §§ 155.120(c) (nondiscrimination rule for Exchanges); 156.200(e) (for QHPs); Health Insurance Market Rules; Rate Review, 78 Fed. Reg. 13,406, 13,438 (Feb. 27, 2013) (to be codified at 45 C.F.R. § 147.104(e)) (for marketing and benefit design); Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation, 78 Fed. Reg. 12,834, 12,867 (Feb. 25, 2013) (to be codified at 45 C.F.R. § 156.125) (for the EHB). See also Letter of Leon Rodriguez to Maya Rupert dated July 12, 2012 (OCR Transaction Number: 12-000800), confirming that Section 1557's sex discrimination prohibition includes discrimination based on gender identity or failure to conform to stereotypical notions of masculinity or femininity, as well as sexual harassment and other forms of sex discrimination regardless of the actual or perceived sexual orientation or gender identity of the individuals involved.

[53] *See, e.g., Goodridge v. Dep't of Pub. Health*, 798 N.E.2d 941, 971 (Mass. 2003) (Greaney, J., concurring); *Baehr v. Lewin*, 852 P.2d 44, 61-63 (Haw. 1993) (plurality opinion); Victoria Schwartz, *Title VII: A Shift From Sex to Relationships*, 35 HARVARD J. L. & GENDER 209 (2012); Anthony E. Varona & Jeffrey M. Monks, *En/Gendering Equality: Seeking Relief Under Title VII Against Employment Discrimination Based on Sexual Orientation*, WM. & MARY J. OF WOMEN & L. 67 (Fall, 2000); Andrew Koppelman, *Why Discrimination Against Lesbians and Gay Men is Sex Discrimination*, 69 N.Y.U. L. REV. 197 (1994); Andrew Koppelman, *The*

to the sex of others, and the person either is eligible to receive a benefit or not depending on whether their sex is "correct" given the sex of the other person.[54] This conclusion follows directly from the cases recognizing that it is race discrimination to base one's eligibility to maintain a relationship with another person upon one's race in relation to the other person's race[55] and the fact that constitutional rights belong to individuals and not to classes or groups.[56]

In addition to the formal analysis, it long has been recognized by scholars and others that sexual orientation discrimination is a form of sex discrimination because it is bias based on a person's failure to conform to the central gender stereotypes that women *should* seek relationships with men, and men *should* seek relationships with women.[57] In the context of marriage, for example, sex-based restrictions reflect stereotyped expectations about the roles each spouse shall perform.[58] And yet, the Supreme Court has taught that our laws "must be applied free of fixed notions concerning the roles and abilities of males

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*Miscegenation Analogy: Sodomy Law as Sex Discrimination*, 98 YALE L.J. 145 (1988). *See also Golinski v. U.S. Office of Pers. Mgmt*., 824 F. Supp. 2d 968, 982 n.4 (N.D. Cal. 2012) (agreeing that refusal to recognize same-sex couples' marriages was discrimination based on sex); *In re Balas*, 449 B.R. 567, 577–78 (Bankr. C.D. Cal. 2011) (concluding federal Defense of Marriage Act was "gender-biased" because it deprived same-sex couples of benefits based on their gender).

[54] *See Goodridge v. Dep't of Pub. Health*, 798 N.E.2d 941, 971 (Mass. 2003) (Greaney, J., concurring)("That the classification is sex based is self-evident. The marriage statutes prohibit some applicants . . . from obtaining a marriage license . . . based solely on the applicants' gender.").

[55] *Loving v. Virginia*, 388 U.S. 1, 11–12 (1967) (invalidating Virginia's anti-miscegenation); *McLaughlin v. Florida*, 379 U.S. 184, 188–96 (1964) (invalidating Florida law banning interracial cohabitation). *See also, e.g.*, Koppelman, *Why Discrimination Against Lesbians and Gay Men is Sex Discrimination*, *supra* note 53, 69 N.Y.U. L. REV. at 211 ("*McLaughlin* thus stands for the proposition (which should be obvious even without judicial support) that if prohibited conduct is defined by reference to a characteristic, the prohibition is not neutral with reference to that characteristic."); Koppelman, *Defending the Sex Discrimination Argument for Lesbian and Gay Rights*, *supra* note 53, 49 UCLA L. REV. at 519. *See also Baker v. State*, 744 A.2d 864, 906 (Vt. 1999) (Johnson, J., concurring in part and dissenting in part) (citing *Loving*).

[56] *Goodridge*, 798 N.E.2d at 970 (Greaney, J., concurring) (discussing cases and observing "[a] classification may be gender based whether or not the challenged government action apportions benefits or burdens uniformly along gender lines. This is so because constitutional protections extend to individuals and not to categories of people.").

[57] *See, e.g.*, Deborah A. Widiss, et al., *Exposing Sex Stereotypes in Recent Same-Sex Marriage Jurisprudence*, 30 HARV. J. L. & GENDER 461, 463–64 (2007); Koppelman, *Why Discrimination Against Lesbians and Gay Men is Sex Discrimination*, 69 N.Y.U. L. REV. at 238 ("[Studies] have consistently found correlations between conventional expectations about gender roles and hostility toward homosexuals.") (citations omitted); Ann C. McGinley, *Erasing Boundaries: Masculinities, Sexual Minorities, and Employment Discrimination*, 43 U. MICH. J.L. REFORM 713 (Spring, 2010); Olivia Szwalbnest, *Discriminating Because of "Pizzazz": Why Discrimination Based on Sexual Orientation Evidences Sexual Discrimination Under the Sex-Stereotyping Doctrine of Title VII*, 20 TEX. J. WOMEN & L. 75 (Fall, 2010); Zachary Kramer, *Heterosexuality and Title VII*, 103 NW. U. L. REV. 205, 232 (2009); Sylvia A. Law, *Homosexuality and the Social Meaning of Gender*, 1988 WIS. L. REV. 187 (1988).

[58] Widiss, *Exposing Sex Stereotypes in Recent Same-Sex Marriage Jurisprudence*, *supra* note 57, at 469 (restrictive marriage statutes discriminate because they rely upon and perpetuate "a system under which men and women occupy different marriage and family roles: men must 'act like husbands' and women must 'act like wives.'").

and females." [59] In fact, the Court has emphasized that "care must be taken in ascertaining whether the statutory objective itself reflects archaic and stereotypic notions."[60] More recent decisions have confirmed and even strengthened this principle.[61]

**(b) Examples of Discrimination against LGB People**

As explained below, three common forms of discrimination against LGB people are (1) refusal to respect the family relationships of same-sex couples and their children; (2) discriminatory insurance coverage and services relating to infertility and assisted reproduction; and (3) lack of respect and cultural competence concerning the non-heterosexual orientation of LGB people.

**i. Refusal to recognize same-sex family relationships in health care settings**

Because this has been a pervasive problem, Lambda Legal has brought claims on behalf of surviving partners against multiple hospitals that had prevented the survivor from being at the bedside of the dying same-sex partner. Here are two examples:

- Washington State residents Janice Langbehn and her three children were kept from the bedside of Janice's dying partner, Lisa Pond, as Lisa lay dying following a brain aneurism during the family's vacation in Florida. Although Langbehn held Lisa's power of attorney, hospital staff refused information from her regarding Pond's medical history. And although a physician admitted there was no medical reason to deny visitation, staff refused her and the children access to Lisa's room for nearly 8 hours, saying they were in an "antigay city and state" and could expect no acknowledgment as family. Lambda Legal sued Jackson Memorial Hospital on behalf of Janice and the couple's children. The case inspired President Obama to issue new visitation guidelines requiring respect for same-sex couples in health care facilities receiving federal funding.[62]
- Robert Daniel and Bill Flanigan were traveling from California to visit family in Maryland when Robert suddenly needed emergency care. Although Robert and Bill were registered domestic partners in California and Bill had Robert's power of attorney, hospital personnel kept Bill from Robert's side, telling him only family was permitted to visit and partners did not qualify. Bill could not inform doctors that Daniel wanted to

[59] *Miss. Univ. for Women v. Hogan*, 458 U.S. 718, 724–25 (1982).

[60] *Id.* at 725.

[61] *See, e.g.*, *Nev. Dep't of Human Res. v. Hibbs*, 538 U.S. 721 (2003); *United States v. Virginia*, 518 U.S. 515, 533 (1996) (forbidding reliance on "overbroad generalizations about the different talents, capacities, or preferences of males and females").

[62] Information about *Langbehn v. Jackson Memorial Hospital*, including the complaint, is at http://www.lambdalegal.org/in-court/cases/langbehn-v-jackson-memorial. The memorandum issued by President Obama requiring equal treatment of same-sex partners for visitation purposes in medical facilities receiving federal funds is here http://www.lambdalegal.org/in-court/cases/langbehn-v-jackson-memorial.

forego life-prolonging measures. By the time Bill was allowed to visit hours later, Daniel had lost consciousness and doctors had inserted a breathing tube. Daniel never regained consciousness and the couple never had a chance to say goodbye. Lambda Legal represented Bill in litigation against the hospital, which spurred policy reform.[63]

### ii. Unequal access to family health insurance for same-sex couples and discriminatory insurance plan terms

Over the years, a great many same-sex couples and their children have experienced discrimination when attempting to access insurance, such as when plans have refused to offer coverage for family members absent a valid marriage, or even with one if it is not recognized in-state. The ACA reduces these problems by making it easier for individuals to obtain insurance, although inequalities may remain as coverage may not be equivalent to what is offered by the plan offered by the employer of one's same-sex spouse or partner. The Supreme Court's decision in *United States v. Windsor*, 133 S. Ct. 2675 (2013), striking down Section 3 of the Defense of Marriage Act (DOMA) means same-sex married couples are to be treated the same under federal law as different-sex married couples in the administration of premium tax credits and cost-sharing reductions as well as Qualified Health Plan spousal coverage. This is a great improvement, although it does not provide equality for married couples living in states that do not honor their marriages for purposes of income taxation of the value of spousal health coverage and other matters.

Separate from the ability to acquire insurance are issues concerning policy terms. With respect to health coverage and provision of medical services concerning infertility and assisted reproduction, LGBT people frequently encounter discrimination. Here are two examples illustrating distinct concerns of women and men, respectively:

- In many health insurance policies that cover infertility treatment, infertility in a woman is defined as the inability to achieve pregnancy through unprotected sexual intercourse with a man for at least one year. This eligibility rule discriminates against lesbians who suffer from the same medical problem as heterosexual women but are not pursuing pregnancy through intercourse with a male partner.[64]
- Dennis Barros and his partner planned to have a child with the assistance of a surrogate mother who would carry an egg fertilized by Barros's sperm. But the clinic they enlisted refused to provide services to Barros, citing an FDA guideline recommending against insemination using anonymous donations from men who have had sex with men in the past five years. Lambda Legal has been representing Barros, explaining that the FDA guideline does not apply to known donors such as Barros. The clinic still refuses to

[63] Information about *Flanigan v. University of Maryland Hospital System*, including the complaint, is at http://www.lambdalegal.org/in-court/cases/flanigan-v-university-of-maryland.

[64] Lambda Legal consulted with the Illinois Department of Insurance on a revision of the state administrative regulation that applies to this issue, obtaining a change that permits equal treatment not only of women with a same-sex partner but also those for whom this method of demonstrating infertility is neither feasible nor fair. Information is at http://www.lambdalegal.org/news/il_20100420_illinois-department-of.

provide care to Barros. The Orlando, Florida Human Rights Board has ruled that discrimination occurred; the case is now pending before the Circuit Court.[65]

### iii. Lack of "cultural competence" – or even basic understanding and respect – for the health needs of LGB people

The following testimonies from Lambda Legal's WHEN HEALTH CARE ISN'T CARING report show that many providers lack even basic understanding of lesbian, gay and bisexual people and what constitutes an appropriately respectful professional interaction, let along the "cultural competence" that enables health providers to address their health needs effectively.

- Michelle of San Jose, California reported: "When I left the U.S. Army in 1993, I moved to Georgia to go to college. As I had a disability from my active duty service, I tried to sign up for the Vocational Rehabilitation and Employment program to pay for my college tuition. In order to qualify for the program, I had to attend an evaluation with the local VA clinic psychiatrist. … [T]he psychiatrist asked me why I had left the Army. I explained that I had come to accept that I was gay … The psychiatrist proceeded to spend the entire rest of our hour convincing me that I was not a lesbian, just 'misguided by some other gals' and that he could 'cure me of my deviancy.' By the end of the hour, I knew my chances of signing up for the program were gone. The psychiatrist even went so far as to offer me free counseling at his 'camp for girls like you to get better.'" [66]
- Gregory of Brooklyn, New York recalled: "I had prostate cancer six years ago. The urologist was fully aware of my sexual orientation. A few years ago I went to the urologist who took over his practice when he retired, for erectile dysfunction. He asked me how hard I'd get on a scale of one to ten, if I saw a beautiful woman. I told him 'I'm gay.' His reaction? 'Very funny.' I didn't find this particularly funny." [67]
- Torrey of Portland, Oregon explained: "I went to visit my school's health clinic for an annual checkup. While I was filling out my health history information sheet, I was pleasantly surprised to find that there was space to indicate whether I was sexually active with male or female partners, the number of partners I'd had, and the type of birth control I used. I thought that this was a great example for LGBT-friendly medical facilities. Unfortunately, when I was called into the exam room, the nurse didn't read the form and proceeded to ask me if I was sexually active and used condoms. When I replied no, and told the nurse that I was a lesbian, she was shocked. After that, the appointment was awkward and I felt as though the nurse was not willing to touch me because of my sexual orientation. It just goes to show you that having a LGBT-friendly form does not make a

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[65] Information about *Barros v. Riggall* including the complaint is available at http://www.lambdalegal.org/in-court/cases/barros-v-riggall.

[66] Lambda Legal, Lesbian, Gay, Bisexual and Transgender (LGBT) People and People Living with HIV Speak Out ("People Speak Out"), http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-people-and-people-living-with-hiv-speak-out.pdf.

[67] *Id*.

clinic LGBT-friendly."[68]

- John, a doctor in East Stroudsburg, Pennsylvania, described his treatment of an 18-year-old high school student: "He [had] moved from the West Coast … because of trouble in school. He was having attacks of sudden shaking and weakness. His mom took him to her primary care provider, who referred him to a neurologist, suspecting temporal lobe epilepsy (a very rare condition). He underwent thousands of dollars' worth of tests—all of which turned out normal. I saw him professionally at the request of his boyfriend. Turns out he had been gay bashed in the bathroom at his old high school. He received death threats … None of his new physicians had asked him about his sexual orientation. It quickly became apparent to me that he was having anxiety or panic attacks …. I treated him with small doses of Lorazepam …. This completely eliminated the attacks. The presumption of heterosexuality and failure of his primary care provider and consulting neurologist led to many costly and unnecessary tests and failure to correctly diagnose and treat his problem."[69]

## B. Intersectional Discrimination

### 1. Discrimination against LGBT youth generally

Under the ACA, mental health care now is among the essential covered health benefits. What constitutes appropriate mental health care for LGBT people was a matter of dispute in past generations when homosexuality was considered a mental illness and transgender identity also was not well understood. The overwhelming consensus of contemporary mental health professions now is that there is no illness in homosexuality or bisexuality per se, and that efforts to change a same-sex orientation through aversion or "conversion" therapy are likely to be ineffective and damaging.[70] Similarly, while medical care may be indicated for those with gender dysphoria, the treatment is to align the body with the brain's internal sense of gender rather than to attempt to change the brain's awareness of its gender or to train the person to display the behavior society expects based on the person's external appearance.

Due to continuing social stigma, however, LGBT people continue to seek or be subjected to mental health counseling represented as having the potential to cure same-sex attraction or gender-variant behavior, despite the evidence that such aversion counseling often is damaging. Consequently, two states have prohibited subjecting minors to these practices, deeming it "unprofessional conduct" warranting discipline from the state licensing board,[71] and other states are considering similar legislation.

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[68] *Id*.

[69] *Id*.

[70] See APA Task Force on Appropriate Therapeutic Responses to Sexual Orientation, *Report of the Task Force on Appropriate Therapeutic Responses to Sexual Orientation*, at 121 (2009), *available at* www.apa.org/pi/lgbt/resources/therapeutic-response.pdf; Joy S. Whitman, *et al. Ethical Issues Related to Conversion or Reparative Therapy* (2006), *available at* http://www.counseling.org/news/updates/2013/01/16/ethical-issues-related-to-conversion-or-reparative-therapy.

[71] California' Senate Bill 1172, 2012 Cal. Stat. 835; New Jersey's A3371, P.L.2013, c.150.

California's law was challenged and recently upheld by the Ninth Circuit Court of Appeals.[72] Lambda Legal submitted an amicus brief in the litigation on behalf of organizations that serve LGBT youth. The brief presents numerous examples of the harms to young people of being subjected to counseling based on the false and discriminatory premise that they should and can change these innate personal characteristics.[73] In its decision upholding the statute, the Ninth Circuit noted that the legislature had relied on the "well-documented, prevailing opinion" amongst the country's major medical and psychological authorities that these practices are ineffective and pose a risk of "serious harm to those who experience it."[74]

The harms of anti-LGBT aversion counseling are discussed here because, for purposes of Section 1557 implementation***, they should be recognized as a prohibited form of sex discrimination***. The only persons targeted for such aversion counseling are those who exhibit or claim a same-sex sexual orientation or other gender-nonconforming behavior. Persons who present with a different-sex sexual orientation and other gender-*conforming* behavior are not counseled that there is something wrong with them that they should attempt to change through an unpleasant, at best, course of medical intervention.

In addition to the personal accounts in Lambda Legal's *amicus* brief of the adverse effects for many young people of aversion counseling, an established body of research shows a link between parental reactions to a child's same-sex sexual orientation or gender non-conforming behavior and that child's subsequent health outcomes. This research on family rejection or acceptance shows:

- There is a predictive link between specific, negative family reactions to a child's minority sexual orientation and serious health problems for these adolescents in young adulthood – such as depression, illegal drug use, risk for HIV infection, and suicide attempts.[75]
- LGB young adults who reported higher levels of family rejection during adolescence were 8.4 times more likely to report having attempted suicide, 5.9 times more likely to report high levels of depression, 3.4 times more likely to use illegal drugs, and 3.4 times more likely to report having engaged in unprotected sexual intercourse, compared with peers that reported no or low levels of rejection by their families.[76]

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[72] *Pickup v. Brown*, 2013 U.S. App. LEXIS 18068, 2013 WL 4564249 (9th Cir. Cal., Aug. 29, 2013).

[73] Brief of *Amicus Curiae* Children's Law Center of California, *et al*., *available at* http://www.lambdalegal.org/in-court/cases/pickup-v-brown-and-welch-v-brown.

[74] *Id*. at *13-*14, citing the legislature's reliance on position statements and reports by, among others, the American Psychological Association, the American Psychiatric Association, The American School Counselor Association, the American Academy of Pediatrics, the American Medical Association, the National Association of Social Workers, the American Counseling Association, the American Psychoanalytic Association, the American Academy of Child and Adolescent Psychiatry, and the Pan American Health Organization.

[75] Caitlin Ryan, PhD, ACSW, *et al*., *Family Rejection as a Predictor of Negative Health Outcomes in White and Latino Lesbian, Gay and Bisexual Young Adults*, PEDIATRICS, Vol. 123, No. 1, pages 346 -352 (Jan. 1, 2009) (doi: 10.1542/peds.2007-3524), *available at* http://pediatrics.aappublications.org/content/123/1/346.full.

[76] *Id*.

- Accepting behaviors of parents and caregivers towards LGBT children are protective against mental health risks, including depression, substance abuse, and suicide.[77]

According to this leading research in this field, Latino male youth report the highest number of negative family reactions to disclosure of a youth's minority sexual orientation in adolescence.[78] A subsequent survey similarly found that Latino LGBT youth identified the need for family acceptance as their top problem and personal priority.[79] A separate study of transgender adults showed a similar correlation between family rejection and increased rates of suicidal attempt; 32 percent of transgender respondents who had experienced acceptance from their families reported that they had attempted suicide, compared with 51 percent of respondents who reported family rejection.[80]

Enforcement of Section 1557 to decrease discriminatory counseling and other biased health services provided to LGBT youth and their families, and to increase medically sound services, is needed urgently because LGBT youth are over-represented in youth homeless populations[81] and in foster care systems[82] with all the adverse health consequences those living situations entail. Numerous studies have determined that family rejection due to a young person's minority sexual orientation and/or gender identity is a main cause of the disproportionate numbers of LGBT youth in these situations.[83] In fact, one study found that 42 percent of LGBT youth in out-of-home care were there due to family rejection or because they had been removed from their families because of conflict over their sexual orientation and/or gender identity.[84]

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[77] Caitlin Ryan, PhD, ACSW, *et al., Family Acceptance in Adolescence and the Health of LGBT Young Adults*, J. Child & Adolescent Psych. Nursing, Vol. 23, No. 4, pages 205–213 (Nov. 2010) (doi: 10.1111/j.1744-6171.2010.00246.x), *available at* http://familyproject.sfsu.edu/files/FAP_Family%20Acceptance_JCAPN.pdf.

[78] Ryan, *et al., Family Rejection, supra* note 75.

[79] Human Rights Campaign Foundation & League of United Latin American Citizens, *Supporting and Caring for our Latino LGBT Youth* (2013), *available at* http://www.hrc.org/files/assets/resources/LatinoYouthReport-FINAL.pdf.

[80] Grant, NTDS, *supra* note 19.

[81] Andrew Cray, *et al., Seeking Shelter: The Experiences and Unmet Needs of LGBT Homeless Youth* (Sept. 2013) *available at* http://www.americanprogress.org/wp-content/uploads/2013/09/LGBTHomelessYouth.pdf.

[82] Mark E. Courtney, *et al., Midwest evaluation of the adult functioning of former foster youth: Outcomes at Ages 23 and 24* (2009), *available at* http://www.chapinhall.org/sites/default/files/Midwest_Study_Age_23_24.pdf.

[83] Shahera Hyatt, *Struggling to Survive: Lesbian, Gay, Bisexual, Transgender, and Queer/Questioning Homeless Youth on the Streets of California* (2011), *available at* http://cahomelessyouth.library.ca.gov/docs/pdf/StrugglingToSurviveFinal.pdf; Laura E. Durso & Gary J. Gates, *Serving Our Youth: Findings from a National Survey of Service Providers Working with Lesbian, Gay, Bisexual, and Transgender Youth who are Homeless or At Risk of Becoming Homeless* (2012), *available at* http://fortytonone.org/wp-content/uploads/2012/06/LGBT-Homeless-Youth-Survey-Final-Report-7-11-12.pdf.

[84] Nico Sifra Quintana, *et al., On the Streets: The Federal Response to Gay and Transgender Homeless Youth* (June 2010), http://www.americanprogress.org/issues/2010/06/pdf/lgbtyouthhomelessness.pdf. *See also* Shannan Wilber, *et al., Child Welfare League of America (CWLA) Best practice guidelines: Serving LGBT youth in out-of-home care* (2009).

One root of the problem is that, "Unlike children and adolescents, in general, who receive services and care in the context of their families, LGB adolescents are typically served as adults as if they have no families, across a wide range of settings."[85] This is particularly misguided – and causes missed opportunities to facilitate family coping and to reduce likelihood of destructive behaviors within the family – because many "parents consider pediatricians and other health providers to be important sources of guidance in childrearing."[86] Indeed, many parents of LGBT children turn to a range of health care providers for support when trying to come to terms with their child's minority sexual orientation and/or non-conforming gender identity. The American Academy of Family Physicians instructs that, "Family physicians are in an ideal position to be aware that their adolescent patients may be dealing with issues of sexual identity or orientation that impact their psychosocial and physical health. Asking open questions about sexual identity and orientation can open a dialogue on family relationships, safe sexual practices, suicide risks and other issues confronting gay, lesbian, bisexual, transgendered and questioning adolescents in a sensitive and accepting atmosphere."[87] This is especially true for LGBT youth, for whom it is essential that health care be supportive and free from sex discrimination. The services they receive should not only support their own wellness but also nurture the accepting family relationships that will influence their long-term health prospects. [88]

### 2. Discrimination against LGBT youth in foster care, juvenile justice and homeless systems

#### (a) The landscape for LGBT youth in out-of-home care

As discussed above, LGBT youth are over-represented in foster care, juvenile justice, and homeless systems. Many enter out- of-home care due to rejection by parents or kinship caregivers and are, therefore, already statistically more likely to have poor health outcomes.[89] Due to the rejection and

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[85] Ryan, *et al., Family Rejection, supra* note 75.

[86] *Id*.

[87] Am. Acad. of Family Physicians, *AAFP Policy Statements: Adolescent Healthcare, Sexuality and Contraception* (1987, 2011 COD), *available at* http://www.aafp.org/about/policies/all/adolescent-sexuality.html.

[88] Indeed, the American Academy of Pediatrics' Task Force on the Family highlights the importance of family support for adolescent development and recommends that pediatricians include assessment of family relationships and behaviors in their practice. Edward L. Schor, MD, *et al*., *American Academy of Pediatrics, Report of the Task Force on the Family*, PEDIATRICS, Vol. 111, No. Suppl. 2, pages 1541– 1571 (June 1, 2003), *available at* http://pediatrics.aappublications.org/content/111/Supplement_2/1541.full.html. *See also* Caitlyn Ryan & Donna Futterman, *Lesbian and gay youth: Care and counseling,* J. ADOLESC. MED., Vol. 8, No. 2, pages 207– 374 (June 1997) (abstract available at http://www.ncbi.nlm.nih.gov/pubmed/10360017) (asking LGB adolescents about their family relationships and experiences with rejection can help providers assess the adolescent's risk profile and how to guide their parents to support the child's health and development).

[89] Caitlin Ryan, et al., *Family Rejection as a Predictor of Negative Health Outcomes in White and Latino Lesbian, Gay, and Bisexual Young Adults*, 123 Pediatrics 346 (2009); Heather M. Berberet, *Putting the Pieces Together for Queer Youth*, 85 Child Welfare 261 (2006).

discrimination that led to placement in out-of-home care settings, LGBT youth are more likely to need behavioral health services in addition to basic medical care.[90]

Although some jurisdictions have nondiscrimination policies and regulations in place to protect LGBT youth in care, many still face harassment and discrimination by child welfare workers, congregate care staff, and others.[91] As a result, LGBT youth are forced out of homes and facilities or flee for their own safety and are less likely to have stable placements while in care. In child welfare cases, LGBT are less likely to return home or to be adopted and as result remain in impermanent situations. For youth involved with the juvenile justice system, moves from detention to home to congregate care can result in multiple medical and behavioral health care providers and inconsistent treatment. Each move to a new foster home, a different homeless shelter, or, in the worst cases, to living on the street, can mean a disruption in health care or a failure to establish a primary physician at all.

Youth of color are over-represented in child welfare, juvenile justice, and homeless systems and LGBT youth of color often experience multiple forms of discrimination while in care. In a Massachusetts study, LGBT youth of color stated they access health care from LGBT-focused facilities because they feel providers in these settings are more knowledgeable about their needs.[92] Youth in the study expressed reluctance to engage in behavioral health care services because of the lack of health care providers' personal knowledge of LGBT people of color.[93]

Transgender and gender non-conforming (TGNC) youth in out-of-home care systems face particular challenges. In group care facilities, transgender youth are often denied supportive counseling, appropriate evaluations, and other medically necessary transgender-related treatments.[94] In some cases, facilities have refused to fill prescriptions from a transgender youth's treating physician. Transgender youth who are denied appropriate treatment are at risk for serious negative health and social consequences, including depression, suicide attempts, and self-treatment (using street hormones and engaging in other medically unsupervised activities for gender transition).[95]

Currently, health care for transgender youth in out-of-home care is a patchwork across the country because youth in care are eligible for Medicaid, but coverage varies widely from state to state. The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. EPSDT is

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[90] National Alliance on Mental Illness, *Mental Health Risk Factors Among GLBT Youth* (2007), *available at* http://www.nami.org/texttemplate.cfm?section=fact_sheets1&template=/contentmanagement/contentdisplay.cfm&contentID=48112.

[91] http://www.nrcyd.ou.edu/lgbtq-youth.

[92] http://www.bostonalliance.org/wprs/wp-content/uploads/2012/02/GLBT-Youth-of-Color-Community-Health-Assessment.pdf.

[93] *Id.*

[94] http://whttp://www.bostonalliance.org/wprs/wp-content/uploads/2012/02/GLBT-Youth-of-Color-Community-Health-Assessment.pdfww.villagecounselingcenter.net/A_GUIDE_FOR_GROUP_CARE_FACILITIES.pdf.

[95] *Id*.

key to ensuring that children and adolescents receive appropriate preventive, dental, mental health, and developmental, and specialty services.[96] States are required to provide any additional health care services that are coverable under the Federal Medicaid program and found to be medically necessary to treat, correct or reduce illnesses and conditions discovered regardless of whether the service is covered in a state's Medicaid plan. It is the responsibility of states to determine medical necessity on a case-by-case basis.[97] This case-by-case basis approach to coverage is a breeding ground for discrimination against transgender youth where so much stigma and misunderstanding persists around their experiences and needs. When procedures that have been recommended by a physician as medically necessary are not covered by the child welfare agency, it puts transgender health care in a unique class as the only type of medically necessary treatment not covered for youth in care.

Because of broader societal changes more youth are now openly identifying as LGBT.[98] Medical and behavior health care providers and the out-of-home care systems serving youth across the country must improve their competency in working with these young people or they will continue to face discrimination and have significant unmet health needs.

**(b) Examples of discrimination in health services experienced by LGBT youth in out-of-home care**

The following two stories, drawn from Lambda Legal's work with these youth, illustrate all-too-common forms of health care discrimination faced by transgender youth, particularly those being raised in foster care systems.

- S.T., a transgender youth of color in foster care, was diagnosed with gender identity disorder. Following WPATH standards, her doctor recommended breast augmentation in addition to a social transition. S.T.'s foster care agency supported her in her social transition and also paid for hormone treatment. However, breast augmentation was not covered by state Medicaid and, therefore, the procedure could only be paid out of discretionary agency funds. S.T. waited nine months for the agency to decide whether to pay for the procedure. Her request ultimately was denied. The agency cited S.T.'s instability and a concern that she might be ill-suited to make such an important decision. S.T.'s attorney asked the family court to require payment and the agency is fighting her request. The agency is now requiring a second opinion by a doctor of its choice and will not allow S.T. or her attorney to provide collateral information or even to speak with the doctor outside of S.T.'s consultation. The agency says S.T. must comply with the second doctor's recommendation even though it has not questioned the qualifications of S.T.'s primary doctor. The agency's decision makers have neither met S.T. nor spoken to her doctor. S.T. is

[96] http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-Periodic-Screening-Diagnosis-and-Treatment.html.

[97] *Id*.

[98] http://www.americanprogress.org/issues/lgbt/news/2013/05/02/62087/improving-the-lives-of-lgbt-americans-beginning-with-our-youth/.

now waiting for a second opinion and the outcome of the family court litigation. Meanwhile, her transition has stopped, exacerbating the symptoms which resulted in the original gender identity disorder diagnosis and contributing to the instability the agency now uses against her.

- P.F., a transgender girl living in the northeast, went into foster care and then later returned home to her mother where problems persisted. Months later, she entered the juvenile justice system and, ultimately, was placed in a group home. Individuals involved in her care from child welfare and juvenile justice systems were not aware of her transgender-related health needs. As a result, every time she was moved her treatment was disrupted and prior treatment recommendations were questioned. P.F. ultimately aged out the system, Medicaid coverage ended when she did, and no health coverage plan was put in place. Her treatment again was compromised.

### 3. Sex Discrimination against Children with Intersex Conditions/Disorders of Sexual Development

One in every 2000 children is born with some form of a disorder of sexual development (DSD), also known as intersex conditions.[99] Misinformation about treatment and inconsistency in treatment are prevalent.[100] Parents are left with a confusing patchwork of policies and recommendations from medical professionals and often are ill-equipped to make fully-informed decisions regarding procedures. As a result, many children with DSD have medically unnecessary gender reassignment surgery performed at a very early age before gender identity develops.

These unnecessary procedures may have life-long and profound negative health implications. Residual effects of surgery or resulting scar tissue from surgery can leave individuals incapable of reproducing or experiencing sexual pleasure.[101] In addition, by unnecessarily deciding gender identity for a child at an age when a child cannot consent, uninformed parents and physicians are inadvertently creating the potential for gender dysphoria and other behavioral health conditions.[102]

The following two examples illustrate the types of health care discrimination faced by children with DSDs, particularly those being raised in foster care systems:

- M.C. was born with an intersex condition – a reproductive or sexual anatomy that does not fit typical definitions of male or female. Children with M.C.'s condition have bodies that are not easily labeled as either male or female. Doctors referred to M.C. as a "true hermaphrodite."

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[99] *See* Advocates for Informed Choice, *What is intersex/DSD?*, http://aiclegal.org/who-we-are/faqs/. *See also* Intersex Society of North America, *How common is intersex?*, http://www.isna.org/faq/frequency.

[100] Intersex Society of North America, *What do doctors do now when they encounter a patient with intersex?*, http://www.isna.org/faq/concealment.

[101] Consortium on the Management of Disorders of Sex Development, *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood* at 28, http://www.accordalliance.org/dsdguidelines/clinical.pdf.

[102] Intersex Society of North America, *What's wrong with the way intersex has traditionally been treated?*, http://www.isna.org/faq/concealment.

M.C. was in the care of the South Carolina Department of Social Services (SCDSS) when doctors, in cooperation with social services employees, decided to perform gender reassignment surgery. Typically, children with these conditions develop as a boy or girl as they grow. Despite not knowing whether 16-month-old M.C. would develop into a man or woman, SCDSS consented to sex-assignment surgery and M.C.'s healthy phallus was removed in an attempt to make M.C. a girl. M.C., now 8, has shown signs of developing a male gender and now identifies as a boy. M.C.'s adoptive parents have filed a lawsuit on his behalf in an attempt to end this practice.[103]

- R.T., a child diagnosed with a rare form of DSD, is in foster care in the northeast. His foster mother is accepting and supportive. R.T. needed extensive testing to determine the proper course of treatment, but child welfare caseworkers were uninformed about DSDs and have large caseloads. As a result of the caseworkers' lack of knowledge and excessive workloads, R.T. and his foster mother waited months for treatment referrals, test results, and recommendations on R.T.'s needs. When the tests finally were ordered they were referred to out-of-state providers due to the limitations of state resources. Administrative hurdles regarding payment for the out-of-state testing caused further complications and delays. In the meantime, R.T.'s foster mother has been forced to assign a gender to R.T. without proper information and recommendations.

### 4. Discrimination against LGBT seniors

For LGBT older adults, the experience of being denied the care they need is prevalent, with research showing that 13 percent of LGBT older adults report having been denied health care or provided inferior care because they are LGBT.[104] Fear of discrimination in accessing care is widespread. For example, in a large-scale study from 2006, 19 percent of gay and lesbian baby boomers had little or no confidence that the health care system would treat them respectfully.[105] Another study showed that, because of concerns about how they will be treated, almost 25 percent of LGBT older adults have not revealed their LGBT status to their primary care physicians. This lack of disclosure often means that LGBT seniors do not sufficiently discuss their sexual health, risks of breast or prostate cancer, hepatitis, HIV risk, hormone therapy, or other risk factors with their doctors.[106] As noted by the American Medical Association, "Unrecognized homosexuality by the physician or the patient's reluctance to report his or her sexual orientation can lead to failure to screen, diagnose or treat important medical problems."[107]

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[103] http://aiclegal.org/

[104] K. Fredriksen-Goldsen, *et al., The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults* (2011).

[105] MetLife Mature Market Institute, *Out and Aging: The MetLife Study of Lesbian and Gay Baby Boomers*, at 14 (2006).

[106] K. Fredriksen-Goldsen, *supra* note 104, *The Aging and Health Report;* R. Klitzman and J. Greenberg, *Patterns of Communication between Gay and Lesbian Patients and their Health Care Providers*, J. of Homosexuality 42(4) (2002).

[107] American Medical Association, Policy H-160.991, *Health care needs of the homosexual population*.

These barriers to accessing health care and the negative consequences from not being able to do so are even more pronounced for transgender seniors than for LGB seniors.[108]

Specifically with regard to home-based health care, LGBT elders who fear harassment will often attempt to "de-gay" their home before a caregiver arrives, including hiding photographs or books, or asking a same-sex partner to leave temporarily. This process can have significant negative impacts on the emotional and physical health of a person who already has serious health care needs.[109]

Finally, LGBT seniors experience a range of discrimination in long term care facilities, including verbal and physical harassment from both staff and other residents, refused admission or attempted discharge, refusal to accept medical powers of attorney from a patient's same-sex spouse or partner, restrictions on visitors, refusals by staff to use the correct name or pronoun for transgender patients, and failure to provide appropriate medical care or treatment.[110]

A study conducted by the National Senior Citizens Law Center, Lambda Legal and others captured many stories of inadequate health care caused by anti-LGBT bias and lack of cultural competence concerning the needs of LGBT elders. Responding to the survey, Jean-Luc D. from Maybee, Michigan told the following story about his partner, Johnny Jones, who was in a skilled nursing facility for four days in 2007:

> The first day the nursing staff "accidentally" pulled out his feeding tube. The second day they "accidentally" injured his urethra after pulling out the catheter or inserting it too forcefully. Johnny had to go to the ER twice in the four days: the first time to treat his damaged urethra and the second time after he was found unresponsive following the trip back from the ER. After that, Johnny's family and I moved him to a bigger hospital in Ann Arbor. I don't know whether the poor care Johnny received was because he is black, or because we are a gay couple. I was at his side all day every day, only leaving to sleep. The bad things happened at night, when I couldn't see what was going on.[111]

Another respondent, C. from Columbia, SC, reported:

> I went for nine days without heart medication during a rehabilitation stay in a nursing home. For 17 days I received another, inappropriate, medication. Even though I had been out for many years, I was so dependent on the nurses that I became afraid. It took all the courage I could muster up to keep pushing the staff to solve the problem.[112]

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[108] K. Fredriksen-Goldsen, *supra* note 104, *The Aging and Health Report*.

[109] Services & Advocacy for GLBT Elders (SAGE) & Movement Advancement Project, *Improving the Lives of LGBT Older Adults*, at 34 (Mar. 2010).

[110] Nat'l Senior Citizens Law Center, *et al., LGBT Older Adults in Long Term Care Facilities: Stories from the Field*, at 9 (2011).

[111] *Id*. at 15.

[112] *Id*.

### C. Discrimination Against People Living With HIV

The ACA will expand access to care for many thousands of currently uninsured and underinsured people living with HIV by prohibiting pre-existing condition exclusions, lifetime and annual benefits limits, and premium rating based on health status. Section 1557 also will help to reduce the more subtle discriminatory practices in health programs and activities that limit access to care for people living with HIV will help to reduce HIV-related stigma and its adverse health effects.[113]

#### 1. Discriminatory Insurance Benefit Designs

People living with HIV have reported significant barriers to accessing treatment even when they have public or private insurance due to discriminatory plan designs including:

##### (a) Monthly limits on prescription drugs or the exclusion of drugs recognized as the standard of care for HIV

Drug formularies should meet the federal HIV treatment guidelines, which are widely recognized as setting the standard of care for keeping people living with HIV healthy.[114] Several Medicaid programs utilize either monthly limits or brand-name only requirements, and these restrictions are a significant barrier to care and treatment for people living with HIV. Private insurers also have utilized limited drug formularies to foreclose access to medications needed by people living with HIV. For chronic and complex conditions like HIV, where the standard of care is evolving rapidly, reference to clinical guidelines is important to ensure that coverage decisions are based on established medical guidelines.

##### (b) High cost-sharing on the medications and services that are considered standard of care for people with HIV

Higher costs – particularly in the form of co-pays, deductibles, and coinsurance – can serve as a discriminatory barrier to care for people living with HIV and other chronic conditions. For instance, even with out-of-pocket caps, placing lifesaving HIV or viral hepatitis medications on specialty tiers that require 25 or 30 percent coinsurance acts as an insurmountable barrier to that treatment by making it unaffordable. When cost-sharing features prohibit access to care, HHS should delineate medical override provisions or exception processes that can be initiated by the enrollee, an authorized representative, or the medical provider (similar to the process in Medicare Part D). Cost sharing – in the form of co-payments, deductibles, and coinsurance – must be evaluated closely to ensure that it is not used improperly to limit access to essential care and treatment.

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[113] HIV Health Care Access Working Group 2012 Policy Priorities, http://66.147.244.246/~aidsconn/hivhealthreformorg/wp-content/uploads/2012/02/HHCAWG_priorities.pdf.

[114] See federal guidelines, including for antiretroviral treatment and prevention and treatment of opportunistic infections at http://aidsinfo.nih.gov/guidelines.

**(c) Utilization management techniques used to deny or restrict access to care for people with chronic and complex conditions**

Requiring step therapy for HIV treatment without a medical override provision or imposing burdensome prior authorization requirements on HIV medications are examples of discriminatory utilization management techniques. Also of concern are requirements that patients buy HIV and other designated medications only through mail-order pharmacies and/or imposition of significant costs for not doing so.[115] In addition to impeding timely access and adherence to medications, this utilization management technique eliminates the opportunity for consultation with one's pharmacist, interferes with management of drug interactions and side effects, and creates confidentiality concerns, particularly for those who must have medications delivered to a place of employment to ensure receipt.

**(d) Insurers refusing to recognize Ryan White Programs as third-party payers**

Because insurance coverage provides people living with HIV access to regular and comprehensive medical care, Ryan White Program funds may be used to purchase private insurance for eligible clients. Many states use their Ryan White/AIDS Drug Assistance Program (ADAP) funds to cover client premium, co-pay, and deductible obligations. However, several state Ryan White/ADAP programs have encountered insurers who refuse to recognize Ryan White/ADAP as a third-party payer. Administrative barriers – such as refusals to accept bulk premium payments or pharmacy refusals to invoice Ryan White/ADAP for co-pay amounts – significantly limit Ryan White clients' meaningful access to comprehensive insurance.

**(e) Barriers to accessing substance use and mental health services**

Access to behavioral health care, including substance use disorder and mental health services is also critical for individuals living with HIV and many others. Yet insurance plans often create barriers for individuals trying to access these needed services. For example, the American Society of Addiction Medicine (ASAM) recently reported that many Medicaid and commercial insurance programs impose significant barriers for individuals seeking Medication Assisted Treatment for opioid dependence, including exclusion of medications such as methadone and buprenorphine, as well as imposing burdensome prior -authorization requirements and step therapy. [116] The ASAM also found that needlessly complex coverage rules limit access similarly. It will be crucial for HHS to scrutinize plans

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[115] *See, e.g.*, "Blue Cross to Allow HIV/AIDS Patients to 'Opt-Out' of Mandatory Mail-Order Rx Program—Blue Cross Settles Lawsuit Alleging Discrimination, Threats to Health & Privacy," http://www.consumerwatchdog.org/case/blue-cross-allow-hivaids-patients-%E2%80%9Copt-out%E2%80%9D-mandatory-mail-order-rx-drug-program-blue-cross-set.

[116] The American Society of Addiction Medicine, *Advancing Access to Addiction Medications, Implications for Opioid Addiction Treatment* (2013), *available at* http://www.asam.org/docs/advocacy/Implications-for-Opioid-Addiction-Treatment.

for practices such as these that discriminate against individuals with behavioral health needs, and to enforce the Mental Health Parity and Addiction Equity Act.

**(f) Medical necessity definitions not based on physician recommendations and supported with medical justifications**

Plans can use medical necessity definitions to limit access to essential treatment for people living with HIV and other chronic and complex conditions. For example, medical necessity definitions that deny access to otherwise covered treatment when a person's health cannot be restored, but where the treatment will help maintain health or prevent deterioration, may exclude people from necessary care. Any medical necessity definition must ensure that treatment decisions are based on physician recommendations and medical justification. Because the application of medical necessity to insurance coverage determinations varies greatly within private insurance coverage, HHS should include analysis of medical necessity definitions and provide examples of impermissible definitions in non-discrimination compliance tools.

**(g) Provider networks that exclude HIV providers or do not identify HIV providers in their directories transparently for prospective enrollees.**

Inadequate physician network size and composition also exclude people living with HIV and other chronic conditions from accessing insurance by excluding providers that can deliver the quality care they need. A plan network that systematically excludes HIV providers violates both network adequacy standards outlined in Qualified Health Plan certification requirements and is a discriminatory plan design practice that forecloses meaningful access to care.

**2. Discriminatory Enforcement of Insurance Rules**

In addition to discriminatory plan designs, people living with HIV also are more likely to experience adverse coverage decisions, including service denials and rescission of coverage. For instance, plans have systematically dropped people living with HIV from coverage for failure to pay premiums timely, while allowing healthier populations to remain in coverage. Because of the potential for irregular enforcement of insurance rules in ways that disproportionately impact people living with HIV, it is essential that HHS monitor the amount and types of adverse coverage decisions to ensure that people living with HIV are not systematically denied coverage.

**3. Stigma and Discrimination in Health Care Settings**

Despite significant social and political equality advances for LGBT people as well as advances in HIV care and treatment, the stigmas associated with a same-sex sexual orientation, a non-conforming gender identity, or HIV-positive status still create significant barriers to care, with the following consequences:

**(a) Individual refusals to treat and excessive precautions during treatment**

People living with HIV report provider refusals to treat them as well as excessive provider precautions during treatment that do not comport with federal HIV treatment or health professional safety guidelines.[117] For instance, in 2009, Lambda Legal brought suit on behalf of a Wisconsin woman who had been denied necessary gall bladder surgery because the surgeon she consulted mistakenly believed her HIV presented an undue risk to the surgical team.[118] That same year, Lambda Legal also represented Dr. Robert Franke, a 75-year-old retired university provost and minister, against the assisted living in Little Rock, Arkansas from which he was evicted abruptly when the facility learned he was living with HIV.[119] Earlier, Lambda Legal had represented Cecil Little, who needed nursing home care during his recovery from two strokes and brain aneurysms.[120] Six different Louisiana facilities refused him upon learning of his HIV status, prompting Lambda Legal to pursue care for little via discrimination complaints with HHS.[121] HIV care providers report similar difficulties when trying to link their patients to other specialty services. Provider refusals to treat as well as excessive precautions when treating people with HIV have been encountered across provider types, including private physicians, dentists, and community health centers.[122]

**(b) Blanket refusal to treat policies**

Some service providers have adopted blanket policies refusing care to people living with HIV. For instance, researchers surveyed 131 skilled nursing facilities, 98 plastic and cosmetic surgeons, and 102 obstetricians in Los Angeles County to determine how many of these institutions had blanket policies of refusing to provide services to people living with HIV. Of the providers surveyed, 46 percent of the skilled nursing facilities, 26 percent of the cosmetic and plastic surgeons, and 55 percent of the

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[117] Lambda Legal, *HIV Stigma and Discrimination in the U.S.: An Evidence-Based Report* (2010), http://data.lambdalegal.org/publications/downloads/fs_hiv-stigma-and-discrimination-in-the-us.pdf.

[118] *See Lambda Legal and ARCW Resolve Discrimination Case on Behalf of HIV-Positive Woman Denied Surgery*, http://www.lambdalegal.org/news/wi_20101228_discrimination-case-resolved. Additional information about the case, *Rose v. Cahee*, is at http://www.lambdalegal.org/in-court/cases/rose-v-cahee-et-al.

[119] Like *Rose v. Cahee*, this case, *Franke v. Parkstone Living Center, Inc*., also settled after the federal district court denied defendants' motion to dismiss, http://www.lambdalegal.org/in-court/cases/franke-v-parkstone-living. The complaint is available at http://www.lambdalegal.org/in-court/legal-docs/franke_ar_20090508_complaint.

[120] Details of the case are at http://www.lambdalegal.org/in-court/cases/in-re-cecil-little.

[121] This matter resolved through the complaint process. http://www.lambdalegal.org/news/la_20031008_la-nursing-home-reverses-course-agrees-to-take-man.

[122] National Women's Law Center, *Health Care Refusals Harm Patients: The Threat to LGBT People and Individuals Living with HIV/AIDS* (2013), http://www.nwlc.org/sites/default/files/pdfs/lgbt_refusals_factsheet_8-6-13.pdf.

obstetricians refused to accept any patients with HIV — and did not have any lawful explanation for their discriminatory practice.[123]

**(c) Men of color who have sex with men report higher rates of stigma**

Black gay men and other men of color who have sex with men (MSM) report high rates of stigma when accessing health care. In 2011, the National Alliance of State and Territorial AIDS Directors (NASTAD) and the National Coalition of STD Directors (NCSD) designed and implemented a survey to explore how community- and institution-level stigma within public health practice negatively affects HIV- and STD-related outcomes.[124] The survey was completed by more than 1,300 health department and community-based organization (CBO) staff, health providers, and community members representing 54 different states and territories. Survey results showed high levels of perceived community-level and institutional stigma directed at Black and Latino gay men and other MSM.

## D. Religion Used To Discriminate Against LGBT Patients

### 1. Discrimination by individual health professionals in secular health care contexts based on the professional's personal religious views about LGBT people and same-sex relationships

Here is a selection of cases in which health professionals invoked protections for their religious liberty as grounds for providing unequal treatment to LGBT patients. The first two concern refusal of routine services to address reproductive and sexual health care needs.

- Guadalupe "Lupita" Benitez was referred for infertility care to North Coast Women's Care Medical Group, a for-profit clinic that had an exclusive contract with Benitez's insurance plan. After eleven months of preparatory treatments, including medication and unwarranted surgery, Lupita's doctors finally admitted they would not perform donor insemination for her because she is a lesbian. The doctors claimed a right not to comply with California's public accommodations law due to their fundamentalist Christian views against treating lesbian patients as they treat others. In a unanimous decision, the California Supreme Court held that religion liberty protections do not authorize doctors to violate the civil rights of lesbian patients, enforcing.[125]

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[123] Brad Sears and Deborah Ho, *HIV Discrimination in Health Care Services in Los Angeles County: The Results of Three Testing Studies* (The Williams Institute, UCLA School of Law, 2006), http://williamsinstitute.law.ucla.edu/wp-content/uploads/Sears-Ho-Discrimination-Health-Care-LA-County-Dec-2006.pdf.

[124] NASTAD/NCSD Stigma Survey Findings Presentation, United States Conference on AIDS (2012), *available at* http://www.nastad.org/Docs/042244_Slides-NASTAD-Stigma%20Seminar-and-Public-Health-USCA-2012-09-24-12-FINAL.pdf.

[125] *North Coast Women's Care Med. Grp., Inc. v. San Diego Cnty. Superior Court (Benitez)*, 189 P.3d 959 (Cal. 2008) (physicians' free exercise rights did not exempt them from law's prohibition against sexual orientation discrimination).

- Washington resident Jonathan Shuffield was denied a medical prescription when his doctor in a secular medical practice claimed a personal religious right to refuse to provide care based on Jonathan's sexual orientation. Lambda Legal negotiated a settlement on Jonathan's behalf in which the doctor and employing medical center agreed to take steps to protect other LGBT patients, including LGBT cultural competence for training physicians and staff and amending the center's antidiscrimination policies.[126]

The following cases illustrate the range of situations in which individual health professionals have asserted claims of a right to discriminate against LGBT people or people living with HIV in a health care setting based on the provider's religious views about LGBT people.

- Counseling student's objections to providing relationship counseling to same-sex couples. *Keeton v. Anderson-Wiley*, 664 F.3d 865 (11th Cir. 2011) (finding student unlikely to prevail on free speech and religious liberty claims challenging her expulsion from counseling program due to her religiously based refusal to counsel same-sex couples, contrary to professional standards requiring nonjudgmental, nondiscriminatory treatment of all patients).
- Physician's objection to working with an LGB person. *Hyman v. City of Louisville*, 132 F. Supp. 2d 528, 539-540 (W.D. Ky. 2001) (physician's religious beliefs did not exempt him from law prohibiting employment discrimination based on sexual orientation or gender identity), *vacated on other grounds by* 53 Fed. Appx. 740 (6th Cir. 2002).
- Proselytizing to patients concerning religious condemnation of homosexuality. *Knight v. Connecticut Dep't of Pub. Health*, 275 F.3d 156 (2d Cir. 2001) (rejecting free exercise wrongful termination claim of visiting nurse fired for antigay proselytizing to home-bound AIDS patient).
- Refusal to process lab specimens from persons with HIV. *Stepp v. Review Bd. of Indiana Emp. Sec. Div*., 521 N.E.2d 350, 352 (Ind. 1988) (rejecting religious discrimination claim of lab technician fired for refusing to do tests on specimens labeled with HIV warning because he believed "AIDS is God's plague on man and performing the tests would go against God's will").

Testimonies received in Lambda Legal's health survey describe similar encounters with health professionals who felt free to express their religiously grounded bias toward LGBT patients:

- Kara in Philadelphia, PA: "Since coming out, I have avoided seeing my primary physician because when she asked me my sexual history, I responded that I slept with women and that I was a lesbian. Her response was, 'Do you know that's against the Bible, against God?'" [127]
- Joe in Minneapolis, MN: "I was 36 years old at the time of this story, an out gay man, and was depressed after the breakup of an eight-year relationship. The doctor I went to see told me that it was not medicine I needed but to leave my 'dirty lifestyle.' He recalled having put other patients in touch with ministers who could help gay men repent and heal from sin, and he even suggested that I simply needed to 'date the right woman' to get over my depression. The doctor even went

[126] *In re Shuffield*: http://www.lambdalegal.org/in-court/cases/in-re-shuffield.

[127] Lambda Legal, People Speak Out, *supra* note 66, at page 1.

so far as to suggest that his daughter might be a good fit for me." [128]

Similar examples of discrimination are all too common. Such treatment demonstrably leads to a distressing encounter for the patient, inadequate care, and future medical care avoidance, with potentially dangerous health consequences. It therefore is essential that the courts continue to rule as they have in the cases cited above that protections for religious liberty do not exempt health professionals from legal duties not to discriminate against patients, any more than is true under the American Medical Association's ethical rules.[129]

Lambda Legal has submitted amicus briefs in challenges to the ACA's contraception coverage requirement brought by proprietors of for-profit businesses.[130] Lambda Legal strongly supports the coverage requirement that includes contraception as an essential preventive care benefit for women. The Lambda Legal brief explains why for-profit enterprises do not have religious freedom rights and, even if they did, the connection between an employer's exercise of religion and its employees' access to contraception through third party plans is too tenuous to constitute a cognizable burden on religious liberty. Were such a religious liberty right to be recognized, it would leave a devastatingly small step from the unduly expansive religion claims employers make in these cases to employer power to impose their religious beliefs even more oppressively on their employees. For example, employers might object to employees' use of HIV medications, to infertility care for lesbians or unmarried non-lesbian women, to treatment of gender dysphoria, to pain management and other end-of-life care, and many more basic health care options individuals should be free to consider with guidance from their physicians rather than coercion from their employers.

### 2. Discrimination against LGBT people by religiously affiliated service providers

When LGBT people receive medical care in religiously affiliated facilities, they may have limited recourse against discrimination under applicable nondiscrimination laws. Accordingly, it is that much more important that institutions that accept public funding be held to the same nondiscrimination

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[128] *Id*. at page 2.

[129] *See, e.g.,* American Medical Association Policies E-9.12, *Patient-Physician Relationship: Respect for Law and Human Rights* ("physicians who offer their services to the public may not decline to accept patients because of race, color, religion, national origin, sexual orientation, or any other basis that would constitute invidious discrimination."); E-10.05, *Potential Patients* ((2) The following instances identify the limits on physicians' prerogative: … (b) Physicians cannot refuse to care for patients based on race, gender, sexual orientation, or any other criteria that would constitute invidious discrimination. … (3) In situations not covered above, it may be ethically permissible for physicians to decline a potential patient when: … (c) A specific treatment sought by an individual is incompatible with the physician's personal, religious, or moral beliefs.") (emphasis added).

[130] *See, e.g.*, Brief of Amicus Curiae Lambda Legal Defense and Education Fund, Inc. In Support of Appellants and For Reversal of the District Court, *Domino's Farms Corporation, et al. v. Sebelius, et al.*, Sixth Circuit Court of Appeals Case No. 13-1654, pages 35-39 (filed Aug 12, 2013) (copy submitted electronically with these comments).

standards as others offering services to patients. Here are two examples of situations in which patients had little notice or opportunity to select a secular provider to ensure protection against discrimination.

- Melody Rose in Wisconin required gall bladder surgery but was refused when the surgeon expressed medically baseless concerns that her HIV posed a threat to him and his surgical team. Lambda Legal represented Melody against the physician and health facility that refused her. The physician and clinic were responsible to Melody under the nondiscrimination laws. However, the court determined that Agnesian HealthCare, Inc., the religiously affiliated corporation that did business with the clinic, was exempt from any liability under the civil rights law.[131]
- Jennifer in Folsom, CA: "I am transgender, a registered nurse and married to my same-sex spouse of 6 years. … [W]e were involved in a car crash and taken by trauma alert ambulance to a hospital … My spouse was more seriously hurt and we were separated at the hospital. I was denied any information about her condition despite identifying myself as her spouse and producing a certified copy of our marriage certificate. This Catholic hospital didn't recognize my status as next of kin so they would provide no information. I had to wait several hours until I was discharged from the ER to visit her and see how she was doing for myself. … No one at the hospital ever apologized for adding to our suffering by denying us what would be usual courtesy if we had fit their standards. Until this happened I had never experienced discrimination in health care—I just couldn't believe it happened to us." [132]

**2. Health Programs and Activities That Should Be Considered Covered By Section 1557**

One of the most significant shortcomings of current federal non-discrimination laws as they apply to health care is that they offer a patchwork of protections applicable only to certain programs, products, and activities. This has left wide swaths of the health care arena outside of any meaningful federal non-discrimination regulation. The language of § 1557 of the ACA – prohibiting discrimination in "health programs and activities" – is broad and should be construed to cover a wide range of activities, including outreach and enrollment activities, Qualified Health Plan certification procedures and approval, Qualified Health Plan activities and procedures, private insurance companies, physicians, and other providers who receive payment from subsidized Qualified Health Plans, programs administered by the Executive branch (including the multi-state Qualified Health Plans and Federal Employees Health Benefits Program (FEHB)); ACA grant and demonstration projects, Medicaid and Medicare, and community health centers.

For LGBT and HIV-positive seniors, it is critical to be clear that this mandate applies not only to doctors' offices and hospitals, but to urgent care centers and "minute clinics," home health care services, and long-term care, assisted living, and skilled nursing facilities. Given both the barriers to health care experienced by LGBT seniors and the generally increased need to access health care as we age, LGBT

[131] Information about *Rose v. Cahee* is at http://www.lambdalegal.org/in-court/cases/rose-v-cahee-et-al.

[132] Lambda Legal, People Speak Out, *supra* note 66, at page 2.

seniors are more likely to need to take advantage of acute care settings.[133] As well, in light of the increased health disparities and decreased social support experienced by LGBT seniors, this population is more likely to need to access home health care services or long term care settings.[134]

**3. Impact, costs and benefits of ending discrimination in health care for people living with HIV.**

HIV-related stigma and discrimination have significant implications for individual health and public health generally, such as:

- **Decreased access to testing**
  Fears of discrimination and stigma lead to delayed testing and late diagnosis of HIV, as well as reluctance to disclose HIV status.[135] Stigma and discrimination-related delays in testing (and consequently delays in identification of HIV infection and delayed access to care and treatment) are particularly troubling given that access to treatment is not only essential for individual health, but is also essential to prevent new infections.

- **Decreased access to care and treatment**
  Stigma and discrimination also negatively impact access to essential care and treatment. Studies have shown that people who report a high level of stigma are more likely to report poor access to care, a regular source of HIV care, and adherence to anti retroviral therapy. [136]

- **Adverse health outcomes**
  Discriminatory refusals to provide health services and denials of coverage result in adverse health outcomes for people living with HIV. Refusals to provide care may result in harmful disruptions in treatment, making medication ineffective. This is true for both provider refusals and insurance denials of necessary HIV medications and treatment.[137] Barriers to accessing medically necessary care are particularly significant for low-income people living with HIV and those living in rural areas, where finding an alternative provider is often impossible.

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[133] K. Fredriksen-Goldsen, *supra* note 104, *The Aging and Health Report*.

[134] SAGE, *supra* note 109, *Improving the Lives of LGBT Older Adults*, at pages 30-34; Nat'l Senior Citizens Law Center, supra note 110, *LGBT Older Adults in Long Term Care Facilities*, at page 4.

[135] Margaret Chesney and Ashley Smith, *Critical Delays in HIV Testing and Care: The Potential Role of Stigma*, 42(7) American Behavioral Scientist (1999).

[136] Jennifer Sayles, et al., The Association of Stigma with Self-Reported Access to Medical Care and Antiretroviral Therapy Adherence in Persons Living with HIV/AIDS, 24(10) Journal of General Internal Medicine (2008).

[137] Kelsey Rounds, et al., Perspectives on Provider Behaviors: A Qualitative Study of Sexual and Gender Minorities Regarding Quality of Care, 44 Contemporary Nurse (2013); National Women's Law Center, Health Care Refusals Harm Patients: The Threat to LGBT People and Individuals Living with HIV/AIDS (2013), available at http://www.nwlc.org/sites/default/files/pdfs/lgbt_refusals_factsheet_8-6-13.pdf.

- **Disproportionate burden of HIV and other STDs on stigmatized populations**
  Stigmatized populations are disproportionately impacted by HIV/AIDS and other STDs.[138] HIV/AIDS disproportionately impacts gay men and other men who have sex with men (MSM), particularly gay men/MSM of color – in the form of higher infection rates, less likelihood of timely linkage to care, and less likelihood of viral suppression.[139] In 2010, black men accounted for 36% of new HIV infections among MSM. The number of new infections among young MSM aged 13-24 increased 22% from 2008 to 2010, with young black gay and other MSM accounting for more than half of new HIV infections among young MSM.

To make headway against the epidemic and to meet the goals of the National HIV/AIDS Strategy, tools and strategies are needed that are aimed at improving prevention, access to care, and retention in care for gay men/MSM, including addressing stigma and discrimination associated with this population.

**Ensuring Access to Health Programs and Activities**

4. **Ensuring access for those with limited English proficiency.**

We strongly support the many ACA provisions requiring consumer assistance, outreach, education, and Marketplace and Medicaid information resources to be available in plain language and to accessible for individuals who have limited English proficiency (LEP), including meeting the Culturally and Linguistically Appropriate Services (CLAS) standards. The CLAS standards as well as the Title VI requirements with respect to services for limited LEP individuals should be applied to services received through ACA outreach and enrollment programs (including Navigators and in-person assisters) as well as Marketplace web portals, written materials, and call centers.

Standards should include both translation of important documents into multiple languages as well as inclusion of a "tagline" in multiple languages that informs recipients that the notice or document is important and how to obtain the document in a different language. Similarly, programs that utilize a call center must ensure adequate voice prompts in different languages alerting callers to availability of translation services. We urge HHS to look to the Social Security Administration's practice of translating materials into fifteen languages and to consider adopting the fifteen-language threshold for all HHS and Marketplace-developed materials.

Navigators and other assister personnel in particular must be able to meet the needs of the communities in which they are working and to provide services in a way that is culturally and

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[138] NASTAD/NCSD Stigma Survey Findings Presentation, United States Conference on AIDS (2012), available at http://www.nastad.org/Docs/042244_Slides-NASTAD-Stigma%20Seminar-and-Public-Health-USCA-2012-09-24-12-FINAL.pdf.

[139] Centers for Disease Control and Prevention (CDC), HIV Among Black/African American Gay, Bisexual, and Other Men Who Have Sex With Men, available at http://www.cdc.gov/hiv/risk/racialethnic/bmsm/facts/index.html.

linguistically competent. Ensuring provision of culturally and linguistically competent assistance, outreach, and education activities is particularly important to ensure that stigmatized and vulnerable populations – for instance, the LGBT community, people living with HIV, and people with mental health or substance use disorder needs – have meaningful access to insurance assistance.

### 5. Particular Needs of LGBT People With Respect To Ending Sex Discrimination

HHS should require that child welfare, juvenile justice, and homeless systems providers are informed about the specific health care needs of LGBT youth of color and knowledgeable regarding LGBT specific health care providers in their communities. HHS should provide information and training on these topics. In addition, the federal government should require that child welfare, juvenile justice, and homeless service providers be knowledgeable about LGBT-focused providers within communities of color and offer those services to youth. Further, the federal government should require that all providers, including behavioral health providers, have specific training regarding the specific experiences and needs of LGBTQ youth of color. Staff at all group homes, psychiatric hospitals, and juvenile detention facilities should be familiar with transgender medical care to ensure that a youth's treatment is not interrupted and should look to a youth treating clinician for treatment planning.[140] HHS should require that child welfare, juvenile justice, and homeless systems providers utilize health care providers that are LGBT competent. Providers make referrals to health care providers in their community and, often, have specific contracts with local providers. HHS should require that all providers used are LGBT competent and affirming.

### 6. Issues Posed for LGBT and HIV-Positive People By New Information Technologies in Health Care Delivery

**HHS should prioritize the use of electronic medical records for youth involved in child welfare, juvenile justice, and homeless systems.** The federal government should acknowledge that while all youth in care may experience disruption in medical care due to placement changes, LGBT youth are at a higher risk for poor health outcomes due to higher incidences of placement disruption than their heterosexual peers. HHS should provide guidance that all children in care are to maintain a principal medical provider. Such a directive would be of particular benefit to LGBT youth. In addition, remote access to electronic medical records would give all youth in care, their caregivers, and their caseworkers the ability o obtain needed information if providers were to change and guarantee some baseline consistency in treatment. Again, such access would be of enormous benefit LGBT youth who are at disproportionate risk of bouncing from placement to placement and clinician to clinician.

In addition, while better continuity of care is possible through increased access to medical records for vulnerable populations, continuing social stigma causes many LGBT people to value confidentiality of personal information such as a history of having transitioned, HIV status, and even a minority sexual

[140] http://whttp://www.bostonalliance.org/wprs/wp-content/uploads/2012/02/GLBT-Youth-of-Color-Community-Health-Assessment.pdfww.villagecounselingcenter.net/A_GUIDE_FOR_GROUP_CARE_FACILITIES.pdf

orientation. As information is more readily retained and accessed by a broad range of health care providers, it will be important to secure appropriate privacy protections and to ensure cultural competence training about the needs of LGBT and HIV-positive individuals.

**Compliance and Enforcement Approaches**

**7. Section 1557 Includes the Enforcement Mechanisms Provided For and Available Under Title VI, Title IX, Section 504, and the Age Discrimination Act.**

It is critical that OCR create and administer a strong enforcement system for this new statute. The success of Title IX in combating sex discrimination demonstrates the importance of strong agency enforcement. The compliance and enforcement procedures used under Title IX and the three other civil rights laws referenced by Section 1557 provide a starting point for establishing procedures under Section 1557. The regulations adopted for Section 1557 must reflect the entire wide range of equitable relief and enforcement mechanisms established and available under those statutes, including agency enforcement as well as the private right of action for monetary damages.

Because the statutes listed in Section 1557 contain a private right of action for a full range of relief, including equitable relief and monetary damages, Section 1557 does as well.[141] Likewise, Section 1557 provides for the full range of agency enforcement and Department of Justice enforcement in court.

The enforcement procedures provided under the laws referenced by Section 1557 are a starting point for developing procedures under Section 1557. Like those laws, Section 1557 must be interpreted to provide for complaints brought on behalf of an individual, a class, or by a third party. Each of these vehicles for agency enforcement is crucial for enforcement under the laws Section 1557 references. Class complaints and third party complaints in particular allow OCR to resolve systemic problems of discrimination, rather than proceeding piecemeal only on behalf of individual complainants. They are especially important in the health care area because of the consequences of allowing system-wide patterns of discrimination to continue. Individual victims of discrimination may be hesitant to file complaints themselves because, for example, they fear retaliation from individuals or entities on which they rely for health care or insurance coverage. This creates a strong disincentive for some to file complaints and reinforces the importance of class and third party complaints.

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[141] In *Cannon v. University of Chicago*, the Supreme Court emphasized the importance of the private right of action to enforcing antidiscrimination statutes. 441 U.S. 677, 704-05 (1979). The Court later determined that money damages are available for intentional discrimination, relying on the longstanding principle that all remedies are presumed to be available to accompany a federal right of action "unless Congress has expressly indicated otherwise." *Franklin v. Gwinnett County Public Schs.*, 503 U.S. 60, 66 (1992). There, the Court stated "Congress surely did not intend for federal monies to be expended to support the intentional actions it sought by statute to proscribe." *Id.* at 74. *See also Guardians Assn. v. Civil Service Comm'n of New York City,* 463 U.S. 582 (1983) (damages available under Title VI for intentional violations); *Consolidated Rail Corporation v. Darrone,* 465 U.S. 624 (1984) (awarding backpay for violation of Section 504 of Rehabilitation Act).

Section 1557 is a powerful proactive tool in OCR's work to combat discrimination in health care. OCR's authority is not limited to responding to complaints under Section 1557. It can—and should—also address discriminatory policies and practices at covered entities through technical assistance, systemic investigations, and compliance reviews of selected entities. OCR has conducted these reviews pursuant to its authority under other civil rights laws.[142] Because Section 1557 is a new law, it is especially important that OCR complete compliance reviews to both identify discrimination and set precedents under this new law. Without knowledge of Section 1557's protection or how to file a complaint, individuals remain vulnerable to discrimination in health care settings and covered entities may well continue discriminatory practices.[143] The results of compliance reviews should also be made public. The reports from such reviews can serve as guidance for other covered entities as to what it means to comply with Section 1557.

**Concerning the needs of people living with HIV**, the ability of § 1557 to eliminate HIV and LGBT-related discrimination in health programs and activities and to advance the health equity goals of the National HIV/AIDS Strategy rests on the extent to which the law's protections are enforced. Section 1557 greatly expands existing civil rights protections and is unprecedented in the scope of providers, activities, and programs it reaches. It is therefore, again, essential that HHS develop regulatory and sub-regulatory guidance that is provider, activity, and program-specific and that provides the necessary details of what constitutes discriminatory activity. For instance, the guidance for healthcare providers should make clear that the definition of disability under the Americans with Disabilities Act Amendments Act of 2009 will be employed in enforcement of § 1557 (as it is has been under Section 504 of the Rehabilitation Act), that any individual living with HIV falls within the scope of § 1557's protections, and that a "direct threat" defense to discriminatory conduct based on actual or perceived HIV status will rarely, if ever, absolve an individual or entity from liability.[144]

In addition, HHS should convene a cross-agency task force to ensure federal alignment as regulations are promulgated and also to ensure that regulations are sufficiently detailed and targeted to provide insurance issuers and new ACA programs and providers the specific guidance they need. For instance, in the Health Insurance Portability and Accountability Act (HIPAA) enforcement realm, identification of practices that violated the non-discrimination provisions in the group insurance market

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[142] *See, e.g.*, Dep't of Health & Human Servs., Office for Civ. Rts., *Compliance Review Initiative: Advancing Effective Communication in Critical Access Hospitals* (Apr. 2013), *available at* http://www.hhs.gov/ocr/civilrights/activities/agreements/compliancereview_initiative.pdf

[143] For instance, staff for the California Health and Human Services Agency, which oversees California's Medicaid program, indicated a lack of complaints to the agency on language access issues in 2011 and 2012. Linda Bennett (AFSCME) interview with Amanda Ream, Organizing Director, Interpreting for California (August 2013). The absence of complaints, however, is not an indication that discrimination does not exist; to the contrary, it suggests that individuals may not know their rights or about the complaint process.

[144] *See* U.S. Department of Justice, Civil Rights Division, Disability Rights Section, "Questions and Answers: The Americans with Disabilities Act and Persons with HIV/AIDS," http://www.ada.gov/aids/ada_q&a_aids.htm ("Can a public accommodation exclude a person with HIV or AIDS because that person allegedly poses a direct threat to the health and safety of others? In almost every instance, the answer to this question is no. Persons with HIV or AIDS will rarely, if ever, pose a direct threat in the public accommodations context.")

through regulations, sub-regulatory guidance, and "insurance standards bulletins" was helpful in identifying what constituted prohibited discriminatory insurance practices. This is particularly important given that recent research has indicated that state regulators as well as insurance issuers are still unclear as to how to develop products and procedures that comply with the ACA's new non-discrimination requirements.[145]

Given the barriers to access to the courts, HHS should create a mechanism for robust administrative enforcement of § 1557, together with a private right of action in federal court after exhaustion of administrative remedies (the process used in enforcement of the Age Discrimination Act). Creating meaningful administrative redress mechanisms, backed by the option to proceed with litigation in court, will increase the likelihood that discrimination of various dimensions and degrees may be appropriately addressed through § 1557.

Moreover, many states have passed rules or regulations specifically prohibiting state enforcement of federal provisions of the ACA. There must be clear procedures in place for individuals living in these states to report instances of discrimination directly to the federal government and to facilitate swift review and enforcement. HHS should develop robust monitoring mechanisms to ensure that facially neutral insurance practices and other health care activities are not used to discriminate against people living with HIV and other people living with complex and expensive conditions. To this end, we suggest that probing but not overly burdensome data collection requirements be used, including data collected from consumer surveys and plan data involving denials of coverage, to monitor compliance at the state and federal levels.

**8. Other issues important to the implementation of Section 1557**

**A. HHS should specify that under 1557 medically necessary transgender health care services for transgender youth receiving Medicaid are covered by EPSDT as "additional health care services."**

By clarifying this point at the federal level, HHS can help alleviate the patchwork approach that has developed across the country due to each state's interpretation of this provision of EPSDT (in the absence of clear federal guidance), as it relates to health care for transgender youth.

**B. HHS should clarify that individuals with intersex/DSD conditions are covered under 1557 and provide protections for children who are not of age to consent to reassignment surgeries.**

In addition to clarifying that individuals with intersex/DSD conditions are covered, HHS recognition would bring much needed attention to this population. While it is not possible to recommend a uniform treatment for individuals with DSDs because every situation is unique, guidance from the

[145] Katie Keith, et al., *Nondiscrimination under the Affordable Care Act, The Center on Health Insurance Reforms, Georgetown University Health Policy Institute* (2013), http://chir.georgetown.edu/pdfs/NondiscriminationUndertheACA_GeorgetownCHIR.pdf.

federal government summarizing current recommended treatment standards, articulating uniform procedures to follow, and directing that accurate, comprehensive information be provide to parents would do a great deal to address a complicated area with profound health implications. In particular, HHS should provide guidance and education for staff in child welfare systems that are responsible for making health care decisions for children with DSD conditions and advocate for legal oversight over non-voluntary gender reassignment surgeries.

Thank you for considering the foregoing information submitted in response to your request.

Most respectfully,

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