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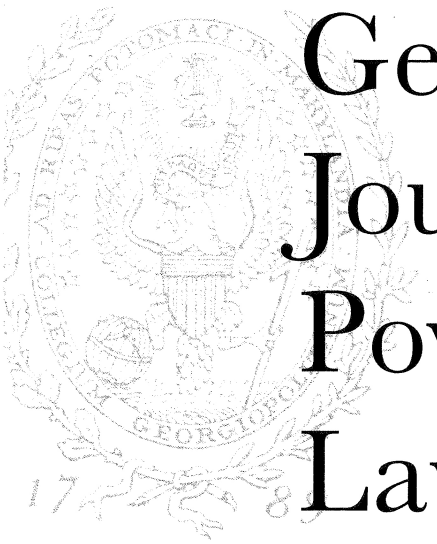

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ESSAY

Outing the Invisible Poor: Why Economic Justice and Access to Health Care is an LGBT Issue

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Written piece related to presentation delivered on November 25, 2008, at Queers for Economic Justice forum in New York, NY entitled "PRICE TAGGED: The LGBTQ Community, Economic Crisis & the Obama Administration." Updated 2010.

One of the largest and most detrimental myths about Lesbian, Gay, Bisexual, and Transgender (LGBT)[1] individuals is that all are affluent, have extensive disposable income, are childless, and are only concerned with issues related to their sexual orientation and/or gender identity.[2] This perception is not only incorrect, but it ignores the multidimensional layers of identity each person experiences. As with every other identity group in society, LGBT individuals (and their children) live in poverty and are in need of the available government support systems. The absence of comprehensive and affordable health care confronts LGBT families and forces these families to choose between health care and other necessities of life, just as it does everyone else in the U.S. Recently passed health care reform will provide assistance and greater coverage for more people, yet many of the problems facing low-income LGBT individuals and families persist. In this current economic crisis, more and more individuals and families are turning to government support, and with the rising cost of health care and increasing difficulty securing health coverage through employment, families can easily find themselves in the position of requiring government assistance.

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1. I have chosen in this essay to use the term "LGBT" to represent the community concerned in the interest of brevity and because it is the most universally understood representation. The use of the term LGBT, however, in no way is meant to exclude those who identify with other terms or references, such as gender-non-conforming/variant individuals, same gender loving individuals, questioning individuals, and those who have chosen to embrace the term "queer" and use it for positive reference.

2. Gender identity refers to the internal sense of one's gender.

I. THE NUMBERS

In understanding the relevance and impact of poverty inside and outside the LGBT community, it is important to first understand the facts and data that show the reality of poverty and access to health care in the United States. According to the U.S. Census Bureau's most recent data, 13.2% of U.S. residents have incomes below the poverty line, and that rate doubles for African-Americans and nearly doubles for Latinos.[3] With regard to health care and those able to access health insurance, there are approximately 59 million people in the United States on Medicaid in a given year—that equals more than one in seven U.S. citizens and more than 15% of U.S. spending on health care.[4] Medicaid is a joint federal and state health insurance program that provides coverage to individuals under the age of sixty-five whose incomes are below a certain level or who suffer from certain illnesses and disabilities. States can also provide coverage for different levels of poverty and different populations above federal minimums for those who are unable to access health care through their employment. Additionally, there are 44 million people on Medicare, the state and federally funded health insurance program for individuals over sixty-five.[5]

This leaves approximately 46.3 million people uninsured—about 18% of the population under sixty-five.[6] Not surprisingly, this rate becomes disproportionate when you look at race and ethnicity.[7] Also, this number does not include the underinsured, who are suspected to have increased from 16 million in 2003 to 25 million in 2007.[8]

Although there is very little exact data with regard to the LGBT population in the U.S., many cities, localities and advocacy organizations have carried out focused studies in recent years or completed extrapolations from other data,

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3. U.S. CENSUS BUREAU, INCOME, POVERTY, AND HEALTH INSURANCE COVERAGE IN THE UNITED STATES: 2008 13 (2009), *available at* http://www.census.gov/prod/2009pubs/p60-236.pdf. According to the federal poverty level issued by the U.S. Department of Health and Human Services every year, in 2009, poverty is considered to be an annual income below $10,800 for adults under 65; $14,570 for 2 people, and $22,050 for 2 adults and 2 kids. Annual Update of the HHS Poverty Guidelines, 74 Fed. Reg. 4199, 4199-4201 (Jan. 23, 2009).

4. Kaiser Commission on Medicaid and the Uninsured enrollment for a fiscal year estimates based on data from Medicaid Statistical Information System (MSIS) reports from the Centers for Medicare and Medicaid Services (CMS) (2009). *See, e.g.*, KAISER COMMISSION ON MEDICAID FACTS, MEDICAID AND THE UNINSURED 1 (Kaiser Family Foundation) (2008), *available at* http://www.kff.org/medicaid/upload/7235_03-2.pdf.

5. U.S. CENSUS BUREAU, MEDICARE ENROLLEES 1990-2007.

6. U.S. CENSUS BUREAU, *supra* note 3, at 20, 22 (Figure 6).

7. KAISER FAMILY FOUNDATION, HEALTH INSURANCE COVERAGE IN THE U.S. 2008 (2008), *available at* http://facts.kff.org/chart.aspx?ch=365.

8. Cathy Schoen, Sara R. Collins, Jennifer L. Kriss & Michelle M. Doty, *How Many Are Underinsured? Trends Among U.S. Adults, 2003 and 2007*, HEALTH AFF. WEB EXCLUSIVE, June 10, 2008, http://www.commonwealthfund.org/Content/Publications/In-the-Literature/2008/Jun/How-Many-Are-Underinsured--Trends-Among-U-S--Adults--2003-and-2007.aspx; *see also infra* note 47 and accompanying text.

which creates a picture of LGBT poverty. Recent data shows that for people ages eighteen to forty-four, 24% of lesbians and bisexual women are living in poverty compared with 19% of heterosexual women.[9] According to the 2000 Census, lesbian couples have a poverty rate of 6.9% compared with 5.4% for different-sexed married couples and 4% for gay male couples.[10] And for the transgender population, advocates recently released the preliminary findings for the first nationwide survey on transgender discrimination and economic disparities, which found that 15% of transgender respondents lived on $10,000 per year or less and transgender individuals experienced double the rate of unemployment as the population as a whole.[11] Further, individual location studies illustrate high levels of poverty for transgender individuals. For example in a Minnesota study, 22% of people who identify as transgender were living below poverty; and in Chicago, 34% were unemployed and 40% were living on less than $20,000.[12] Although comprehensive nationwide data is still difficult to ascertain, these statistics clearly debunk the myths outlined above and show that LGBT individuals and families live in poverty in substantial numbers.

Cross-referencing poverty with access to health care in general in the LGBT community demonstrates the importance of these issues. There is very little exact data on LGBT access to health care, but many qualitative studies show LGBT individuals are more likely to face barriers to access and preventative care, and this is even more true if one is a person of color or disabled. An online national survey from 2002 found that 30% of LGBT responders claimed they did not have health insurance, compared to only 14% of their heterosexual-identified counterparts.[13] Focused surveys on LGBT health have found that LGBT individuals are less likely to be insured, particularly if young, unemployed, poor and/or African-American.[14] Additionally, studies carried out in some of the U.S.'s largest cities showed that: in Los Angeles, 70% of heterosexual women are

9. RANDY ALBELDA, M.V. LEE BADGETT, GARY J. GATES & ALYSSA SCHNEEBAUM, POVERTY IN THE LESBIAN GAY AND BISEXUAL COMMUNITY i (The Williams Institute) (2009).

10. *Id.* at 5.

11. NATIONAL CENTER FOR TRANSGENDER EQUITY ET AL., PRELIMINARY FINDINGS, NATIONAL TRANSGENDER DISCRIMINATION SURVEY (2009), *available at* http://www.thetaskforce.org/downloads/reports/fact_sheets/transsurvey_prelim_findings.pdf

12. *An Examination of Discrimination against Transgender Americans in the Workplace: Hearing Before the H. Subcomm. on Health, Employment, Labor, and Pensions*, 110th Cong. (2008) [hereinafter *Transgender Discrimination Hearing*] (statement of the National Gay and Lesbian Task Force Action Fund), *available at* http://www.thetaskforce.org/downloads/misc/Task_Force_Action_Fund_Testimony_6_26_08_FINAL.pdf.

13. HARRIS INTERACTIVE ET AL., FEWER THAN HALF OF ALL LESBIAN, GAY, BISEXUAL, AND TRANSGENDER ADULTS SURVEYED SAY THET HAVE DISCLOSED THEIR SEXUAL ORIENTATION TO THEIR HEALTH CARE PROVIDER (2002), *available at* http://www.witeckcombs.com/news/releases/20021217_health.pdf.

14. GAY AND LESBIAN MEDICAL ASSOCIATION, HEALTHY PEOPLE 2010, COMPANION DOCUMENT FOR LGBT HEALTH 50 (2001) (citing J. BRADFORD & C. RYAN, THE NATIONAL LESBIAN HEALTH CARE SURVEY (1988)).

insured, compared to 63% of lesbians and 42% of bisexuals;[15] 16% of men who have sex with men lack health coverage;[16] and in the transgender community, a 1999 New York City survey found that 20% had no coverage;[17] and a 2000 Washington, D.C. study found that 47% of transgender individuals had no coverage, a number that increased for people of color.[18] These numbers alone should dispel the myth of the affluent LGBT individual and couple, which many people both within and outside the LGBT community believe is the truth. These numbers show that economic justice and access to health care are issues that LGBT individuals and activists should be thinking about.

II. Access to Public Health Coverage

Access to health care, particularly the state and federally funded programs of Medicaid and the State Children's Health Insurance Program, is an issue that touches everyone in the U.S. Throughout the country, barriers to access abound. Some states are more generous than others, but all erect barriers and obstacles to attaining eligibility for such programs—sometimes in an effort to save money, but also sometimes in an effort to draw distinctions between those who are considered "deserving" and those who are not. Once an individual or family has achieved the goal of establishing eligibility for these programs, further barriers and obstacles are placed in the way of achieving true comprehensive and culturally competent coverage. I encourage the LGBT community to focus on these barriers to access to state and federally funded health care, in addition to advocating for streamlined and comprehensive access to health care for all those in need.

LGBT individuals and families suffer certain barriers to access based on identity, family structure, and targeted needs. Traditional definitions of family and sexual regulation restrict LGBT individuals from accessing Medicaid and the Children's Health Programs. Medicaid, unlike food stamps for example, defines families based on legal relationship and not household.[19] In Medicaid programs throughout the country, larger families are permitted higher incomes, but family members with no recognized legal relationship are not counted in the family size determination.[20] Therefore, many people will be determined ineligible if they are

15. *Id.* (citing A.L. Diamant et al., *Health behaviors, health status and access to and use of health care: A population-based study of lesbian, bisexual and heterosexual women*, 9 Archives of Fam. Med. 1043-1051 (2000)).

16. *Id.* (citing R. Stall, Los Angeles Gay and Lesbian Center, Access to health care among men who have sex with men: Data from the Urban Men's Health Study (2000)).

17. *Id.* (citing K. McGowan, HIV Prevention Planning Unit, Transgender Needs Assessment (New York City Department of Health) (1999)).

18. *Id.* (citing J.M. Xavier, The Washington Transgender Needs Assessment Survey (Administration for HIV and AIDS of the District of Columbia) (2000)).

19. 42 C.F.R. § 435.602(a)(1), (b)(2).

20. *Id.*

applying as a family of one, whereas they would qualify as a family of two or more.[21] Health care reform will eventually raise the level of income a family may have and still qualify for Medicaid, but the household definitions remain the same.[22] Additionally, Medicaid provides that individuals do not have to become impoverished in order for their elderly spouse to receive nursing home or long-term care.[23] Such a benefit is not available to same-sex couples.

Many states do not provide Medicaid coverage for single childless adults.[24] This prohibition implicates relationship recognition issues and definitions of parentage that are a barrier to health care for LGBT individuals and families. In these states, non-disabled or non-pregnant adults are only eligible for Medicaid if they are a parent of a minor child, and such legal relationships are often defined very narrowly and through traditional means.[25] The recently passed health care reform legislation provides some limited funding for coverage of single-childless adults, but the immediate impact will be minimal and, although helpful, this expansion will not cover the entire group concerned. Furthermore, when accessing children's health programs, families can experience complications in determining the legal responsibility for the child, and thus who is counted as a family member. The expansion of second parent adoption and family law that recognizes parentage through actions other than judicial decree can help cut across these traditional definitions. But even so, such barriers and extra complications can act as deterrence for families seeking government assistance.

The initial application forms and the initial eligibility interviews also can act as a deterrent to LGBT individuals and families seeking assistance based on their heterosexual slant.[26] These forms have limited definitions of marital status, do not offer space for transgender applicants to identify themselves and their

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21. It should be noted that in some circumstances, if the Medicaid application included income from both partners, rather than solely one individual, the applicant would be determined ineligible because of too much income. Furthermore, in jurisdictions that perform same-sex marriages or recognize legal same-sex marriages entered into in other jurisdictions, definitions of spouse and family may incorporate these unions. *See, e.g.*, NEW YORK STATE DEP'T OF HEALTH, MEDICAID REFERENCE GUIDE, CATEGORICAL FACTORS 2.1 (2009).

22. Under the new health reform legislation, states will receive federal funding to cover individuals and families with up to 133% of the federal poverty level from January 2014. Certain states that already cover 100% will be able to receive a phased-in increase in federal funding for non-pregnant childless adults in this income bracket. Unfortunately, there are only a handful of states that currently provide health coverage above this limit.

23. 42 U.S.C. § 1396r-5(h).

24. KAISER FAMILY FOUNDATION, MEDICAID AND STATE FUNDED COVERAGE INCOME ELIGIBILITY LIMITS FOR LOW-INCOME ADULTS, 2009 (2009), *available at* http://www.statehealthfacts.org/comparereport.jsp?rep=54&cat=4&sub=54 [hereinafter KAISER FAMILY FOUNDATION, MEDICAID].

25. In Virginia, for example, the state does not provide Medicaid coverage for childless adults unless they are disabled, elderly, pregnant, or a limited amount of refugees. *See* VA. DEP'T OF SOC. SERVS., VIRGINIA MEDICAID MANUAL: MEDICAID COVERED GROUPS 1-4 (2009), *available at* http://www.dss.virginia.gov/files/division/bp/medical_assistance/manual_transmittals/manual/m03.pdf.

26. PUBLIC ADVOCATE OF THE CITY OF NEW YORK, IMPROVING LESBIAN, GAY, BISEXUAL, AND TRANSGENDER ACCESS TO HEALTHCARE AT NEW YORK CITY HEALTH AND HOSPITALS CORPORATION FACILITIES 9-10 (2008), *available at* http://transgenderlegal.org/media/uploads/doc_84.pdf. This portion

gender-identity, nor specify their preferred name or gender. A recent study by the Public Advocate in New York City found that the health care environment is heterocentric and gender normative, as well as discriminatory and homophobic.[27] The study found that concerns about homophobia and discrimination often keep LGBT individuals from using health care services.[28]

III. Access to Services

Full-scale relationship recognition or legalizing of same-sex marriage will not solve all LGBT-specific issues related to access to state and federally funded health care programs. LGBT individuals and families also suffer discrimination and disparate access once determined eligible. Most states, for instance, exclude transition-related health care and cross-gender care.[29] For example, since 2004, New York State has specifically prohibited transition-related care, services, drugs, or supplies.[30] When New York State implemented this regulation, denials occurred because Medicaid would only cover hormone treatment for individuals whose sex on their identity documents matches the hormone they were requesting.[31] Upon implementation, many transgender individuals who had received treatment for years had to either discontinue hormone treatment or pay for these very expensive treatments out of their own pockets.[32] These barriers can often send people to "black market hormones," which some studies show account for 29-63% of those taking hormone treatment therapy in urban areas, mostly male-to-female.[33] In 2006, Congress added another wrinkle by requiring all Medicaid recipients to document both citizenship and identity, thus requiring further documentation where a person's listed sex and gender identity may differ.[34]

Many states' Medicaid programs include a disparity in provision of certain medical services that are important to LGBT individuals and families. For example, although fifteen states mandate private health insurance coverage of infertility treatments, including assisted reproductive technologies, only three

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of the study is related to medical intake forms at hospitals but the same can be said for Medicaid application and interview forms.

27. *Id.* at 7-9.

28. *Id.* at 8-9.

29. Examples of cross-gender related care are pap tests for transgender men or prostate exams for transgender women.

30. 18 N.Y.C.R.R. § 505.2(l); *see also Casillas v. Daines*, 580 F.Supp.2d 235 (S.D.N.Y. 2008) (holding that regulation did not violate the Equal Protection Clause of the United States Constitution and the relevant provisions of the Medicaid Act were not enforceable under 42 U.S.C. § 1983).

31. In addition to the regulation prohibiting such services, this statement also comes from my personal experience assisting individuals at the Transgender Legal Clinic at the LGBT Community Center in New York City with the legal name change process, which many individuals reported were hoping would lead to formal gender changes to their identifying documents.

32. Kaiser Family Foundation, medicaid, *supra* note 24; *Casillas*, 580 F.Supp.2d.

33. Gay and Lesbian Medical Association, *supra* note 14, at 47.

34. 42 U.S.C. § 1396b(x).

states' Medicaid programs cover any infertility-related treatment under family planning waivers.[35] Assisted reproductive technologies and other treatment that is categorized as infertility treatment can be of great importance to same-sex couples and many LGBT individuals who choose to have children. Medicaid also accounts for the largest financing of HIV/AIDS-related care in the U.S. and those living with HIV and AIDS continue to battle for comprehensive coverage.[36]

Medicaid recipients also have far fewer medical providers to choose from, particularly in non-urban areas, and, thus, it can be difficult to find providers who are culturally competent and do not operate from a heterosexual focus, especially in the area of sexual health. As noted above, homophobia, transphobia and discrimination are barriers that can often lead to delays in seeking care or avoidance of preventative care and treatment. Several organizations have begun offering and encouraging trainings related to LGBT culturally competent health care and it is important that such outreach reach providers who take Medicaid.[37] Nevertheless, another recent study demonstrates that LGBT individuals experience discrimination, substandard care (including the use of hard and abusive language or refusal to even touch the patient), and full-out denial of care.[38] This study also found that incidents of substandard care were even higher amongst low-income individuals.[39]

There are also extensive economic justice issues facing LGBT young people. Homelessness is on the rise and many of the youth interacting with the foster care and criminal justice systems identify as LGBT.[40] Advocates have made great strides in training social workers and children services' staff in the best practices for serving LGBT youth in out-of-home care.[41] These best practices often do not

35. KAISER FAMILY FOUNDATION, STATE COVERAGE OF FAMILY PLANNING SERVICES 12-13 tbl. 4 (2009) [hereinafter KAISER FAMILY FOUNDATION, STATE COVERAGE]. Although it should be noted that some private health insurance companies also do not cover certain expensive assisted reproductive activities, such as in-vitro fertilization, the state Medicaid plans go further and do not cover any preconception care services beyond standard gynecological exams. *See also* 42 U.S.C § 1396r-8(d)(2)(B) (listing as restricted drugs those used for infertility).

36. KAISER FAMILY FOUNDATION, HIV/AIDS POLICY FACT SHEET (2006), *available at* http://www.kff.org/hivaids/upload/7172-03.pdf.

37. For example, GLBT Health Access Project at JRI Health has developed a Community Standards of Practice for Provision of Quality Health Care Services for GLBT Clients; the Gay and Lesbian Medical Association also has guidelines for care of LGBT patients; and Kaiser Permanente provides a handbook entitled "Treatment Not Judgment: Delivering Culturally Competent Care to LGBT Members."

38. LAMBDA LEGAL, WHEN HEALTH CARE ISN'T CARING: LAMBDA LEGAL'S SURVEY ON DISCRIMINATION AGAINST LGT PEOPLE AND PEOPLE LIVING WITH HIV (2010), *available at* www.lambdalegal.org/health-care-report.

39. KAISER FAMILY FOUNDATION, STATE COVERAGE, *supra* note 35, at 11.

40. In 2006, national studies found that 20-40% of the homeless youth population identify as LGBT. NATIONAL GAY AND LESBIAN TASK FORCE POLICY INSTITUTE, LGBT YOUTH: AN EPIDEMIC OF HOMELESSNESS 13 (2006).

41. JODY MARKSAMER, CAITLIN RYAN & SHANNAN WILBER, CHILD WELFARE LEAGUE OF AMERICA BEST PRACTICE GUIDELINES: SERVING LGBT YOUTH IN OUT-OF-HOME CARE (Child Welfare League of America) (2006).

extend to their counterparts in public benefits agencies. Negative treatment by workers, as well as concrete barriers, such as requiring certain-aged children who do not live with their parents, but whom are also not cared for through the foster care system, to declare themselves emancipated in order to receive Medicaid for themselves apart from their parents,[42] keep LGBT youth in poverty from receiving quality health care. If a youth is placed in foster care, the young person automatically receives Medicaid, but can lose it immediately upon discharge, unless provisions are made and followed to encourage a seamless transition to independent living.[43] No reliable statistics show exact numbers, but those who work in child welfare and juvenile justice systems also report that LGBT youth are disproportionately represented among youth in out-of-home care.[44] And, not surprisingly, in relation to culturally competent care discussed above, youth can suffer from even greater barriers and prejudices when discussing sexual health and mental health issues with providers.

IV. WAY FORWARD

I hope that this snapshot of specific issues confronting LGBT individuals and families interacting with the Medicaid and Children's Health systems in the U.S. demonstrates how LGBT advocates, activists, and individuals need to think beyond just pure equality concerns and push for an agenda that creates a system of comprehensive, culturally competent, and affordable health care for all. Achieving this goal is not just about encouraging single-axis LGBT organizations to think about issues of economic justice and access to health care, but also by forging relationships and collaborations with groups that focus on general issues of economic justice and access to health care.

Action for the future, both on the national scale and in our local communities, must incorporate several different messages when advocating for greater access to health care. The issue is not solely about universal coverage itself, but comprehensive coverage.[45] In many health insurance plans traditionally proposed in Washington, including the most recent debate, high deductable plans

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42. *See, e.g.*, 18 N.Y.C.R.R. § 349.5; *see also* 42 C.F.R. § 435.403(h).

43. AMERICAN PUBLIC HUMAN SERVICES ASSOCIATION, MEDICAID ACCESS FOR YOUTH AGING OUT OF FOSTER CARE (2007), *available at* http://www.aphsa.org/home/Doc/Medicaid-Access-for-Youth-Aging-Out-of-Foster-Care-Rpt.pdf. In 2007, seventeen states had enacted legislation to automatically extend Medicaid coverage under the federal Foster Care Independence Act of 1999, and five other states reported having plans to do the same.

44. MARKSAMER ET AL., *supra* note 41, at 1.

45. A stark example frequently used by the health care advocacy community is of a person who is provided a wheelchair, but not provided the battery needed to operate the wheel chair. Additionally, non-comprehensive health insurance policies are ones with such high deductibles that individuals and families are unable to access regular or preventative care. A final example is of women who have undergone mastectomies as a result of breast cancer and are denied coverage for physical therapy needed to overcome certain joint and muscle problems experienced as a result of the mastectomy, because the coverage only covers physical therapy that is needed as a result of the cancer itself.

that provide only forms of catastrophic coverage feature prominently. Real progressive options need to be based on reality and evidence, particularly around preventative care. The new health reform legislation addresses issues of preventative care by requiring new health care coverage to include wellness visits for certain populations; however even with such progress, obstacles remain to comprehensive coverage and equal access. This particular concern ties back to the problem of underinsurance described above—individuals who have insurance in theory, but in practice lack access to day-to-day acute and preventative care. These individuals often pay high premiums, yet are not adequately protected from high medical expenses, and, thus, frequently go without needed care.[46] We must continue to push for comprehensive coverage, not just extensions of our already existing systems.

To accomplish this, an area that we must also encourage our national and local leaders to focus on is the cost of health care. According to the World Health Organization, the U.S. spends 15.3% of GDP on health care;[47] rising to 19.3% by 2019.[48] In comparison, the United Kingdom's universal single-payer coverage system accounts for 8.4% of the United Kingdom's GDP.[49] This is astonishing. Although health care reform has attempted to address costs, additional measures to reduce costs are still necessary if we are to have truly universal and comprehensive health coverage in the U.S.

V. Conclusion

Economic justice and access to health care is an LGBT issue that deserves the communities' attention and advocacy. It is not just about raising awareness of the particular barriers LGBT individuals and families face—but lending a greater voice to all who live in poverty. These are issues that deserve everyone's attention and advocacy, and maybe we now have an administration that will listen.

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46. Cathy Schoen et al., *supra* note 8.

47. World Health Organization, Country Profile and Statistics: United States (2009), http://www.who.int/countries/usa/en/.

48. Center for Medicare and Medicaid Services, National Health Expenditure Projections 2009-2019 (2009), *available at* http://www.cms.gov/NationalHealthExpendData/downloads/proj2009.pdf.

49. World Health Organization, Country Profile and Statistics: United Kingdom (2009), http://www.who.int/countries/gbr/en/.