August 13, 2019

Roger Severino
Director, Office for Civil Rights
U.S. Department of Health and Human Services
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

RE: HHS Docket No. HHS-OCR-2019-0007, RIN 0945-AA11, Comments in Response to Section 1557 NPRM

Dear Mr. Severino:

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

We write to express our opposition to the U.S. Department of Health and Human Services (HHS) notice of proposed rulemaking (NPRM) on Section 1557 of the Affordable Care Act. The proposed rule would severely undermine well-established rights of individuals with disabilities, negatively impacting people with disabilities and chronic conditions, their families, and communities. The proposed rule lacks any reasonable basis for altering settled law, and increases the likelihood of discrimination against people with disabilities in the critical area of health care financing and access to care. The undersigned members of the CCD therefore urge HHS not to finalize this regulation in whole or in part.

Section 1557 and its implementing rules are critical because people with disabilities are routinely discriminated against in the provision of health care. People with disabilities experience significant health disparities and barriers to health care, as compared with people who do not have disabilities, and too often, people with disabilities have been

and continue to be denied equal access to quality health care.[1] In addition, people from minority groups who also have disabilities confront an enormous health disparity amplifying phenomenon.[2]

Prior to the ACA, health insurance companies routinely discriminated against people with disabilities by simply denying coverage to individuals with preexisting conditions, charging higher premiums to people with disabilities, and imposing annual and lifetime caps on benefits – all of which disproportionately affect people with disabilities.[3] Congress passed the ACA to put an end to these discriminatory practices.[4] The ACA also sought to end discrimination in the types of health benefits offered by requiring most individual and small group health plans to provide comprehensive health benefits in ten broad categories of coverage, known as Essential Health Benefits (EHBs).[5] Section 1557 of the ACA is one important mechanism to enforce these statutory mandates.

Health care entities also discriminate against people with disabilities by failing to provide accessible facilities, effective communication, and reasonable modifications to enable people with disabilities to access health care. Section 1557 and the 2016 Final Rule implementing it created straightforward and comprehensive rules to remedy these

---

[1] *See, e.g.,* Tara Lagu et al., *The Axes of Access – Improving Care Quality for Patients with Disabilities*, 370 N ENG. J. MED. 1847 (2014); Tara Lagu et al, *Ensuring Access to Health Care for Patients with Disabilities*, 175 J. AM. MED. ASS'N INTERNAL MED. 157 (2014); Tim Gilmer, *Equal Health Care: If Not Now, When?*, NEW MOBILITY (July 1, 2013), http://www.newmobility.com/2013/07/equal-health-care-if-not-now-when/; Gloria L. Krahn et al., *Persons with Disabilities as an Unrecognized Health Disparity Population*, 105 AM. J. PUB. HEALTH (S198-S206) (2015); Kristi L. Kirschner et al., *Structural Impairments That Limit Access to Health Care for Patients With Disabilities*, 297 J. AM. MED. 1121-5 (2007); Lisa I. Iezzoni, *Eliminating Health and Health Care Disparities Among the Growing Population of People with Disabilities*, 30 HEALTH AFFAIRS 1947-54 (2011).

[2] *See, e.g.,* R. N. Blick et al., *The Double Burden: Health Disparities Among People of Color Living with Disabilities,* OHIO DISABILITY AND HEALTH PROGRAM (2015); R. Whitley & W. Lawson, *The Psychiatric Rehabilitation of African Americans With Severe Mental Illness*, PSYCHIATRIC SERVICES, 508-11 (2010) (African Americans with severe mental health disabilities are less likely than whites to access mental health services, more likely to drop out of treatment, more likely to receive poor-quality care, and more likely to be dissatisfied with care).

[3] *See generally, e.g*. Valarie K. Blake, *An Opening for Civil Rights in Health Insurance After the Affordable Care Act,* 36 B.C. J.L. & SOC. JUST. 235 (2016) (describing pre-ACA health insurance discrimination and how the ACA addressed those issues); Sara Rosenbaum et al., *Crossing the Rubicon: The Impact of the Affordable Care Act on the Content of Insurance Coverage for Persons with Disabilities*, 25 NOTRE DAME J. L. ETHICS & PUB. POL'Y 235 (2014) (describing ACA nondiscrimination provisions and focusing on the function of essential health benefits).

[4] 42 U.S.C. §§ 300gg–4; 300gg-11.

[5] 42 U.S.C. § 18022.

barriers. We see no reason for HHS to muddy these waters and undermine these important protections.

HHS underwent an extensive process to develop regulations for Section 1557, including a Request for Information, proposed rule, and final rule.[6] HHS considered more than 24,875 public comments prior to finalizing the 2016 rule.[7] This new proposed rule ignores the reasoned process HHS has already undertaken. Furthermore, Congress has repeatedly rejected attempts to repeal the ACA.[8] HHS' proposal to rewrite or eliminate regulations implementing Section 1557 is nothing less than an end run around the ACA's statutory protections against discrimination.

Below, we offer comments on some of the proposed changes that will harm individuals with disabilities. Specifically, the NPRM:

1. Impermissibly limits the scope of application of Section 1557;
2. Deletes or substantially weakens sections of the rule designed to prohibit discrimination against people with disabilities, including provisions related to the notice and grievance process, the availability of auxiliary aids and services, the general prohibition on discrimination, specific prohibitions on discriminatory benefit designs and discrimination on the basis of association, and 1557's enforcement mechanisms; and
3. Asks for information on other provisions important for people with disabilities, including whether entities with fewer than 15 employees should even have to provide auxiliary aids and services to people, and whether some multistory entities should have to provide elevators—changes that would invariably harm access to health care for people with disabilities.

I. Proposed "Scope of Application" (Proposed § 92.3)

The proposed rule erroneously interprets Section 1557 to restrict its application to many health insurers. The Civil Rights Restoration Act (CRRA), by its terms and those of Section 1557, does not limit the application of Section 1557. Moreover, the proposed rule incorrectly incorporates the Civil Rights Restoration Act (CRRA) into Section 1557 to limit the scope of Section 1557's coverage of health insurers. We also object to proposed changes that narrow the scope of the rule as it applies directly to HHS

[6] 78 Fed. Reg. 46558 (Aug. 1, 2013); 80 Fed. Reg. 54172 (Sept. 8, 2015); 81 Fed. Reg. 31376 (May 18, 2016).
[7] 81 Fed. Reg. 31376 (May 18, 2016).
[8] See C. Stephen Redhead & Janet Kinzer, *Legislative Actions in the 112th, 113th, and 114th Congresses to Repeal, Defund, or Delay the Affordable Care Act*, CONG. RES. SERVICE (Feb. 7, 2017), available at: https://fas.org/sgp/crs/misc/R43289.pdf.

programs and health programs that receive federal financial assistance (FFA) from HHS.

A. A "Health Program or Activity" Includes Providing Health Insurance Coverage

The proposed rule misreads the clear statutory language and purpose of Section 1557 by applying the CRRA, a prior-enacted law that does not by its terms limit the scope or application of Section 1557, to severely limit Section 1557's application to health insurers.[9] Section 1557 prohibits disability-based discrimination in "any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under this title [of the Affordable Care Act]."[10]

HHS's 2016 interpretation of "health program or activity" to include health insurers (and, in accordance with the statutory language, to cover all of these insurers' activities if any part of their operations receives FFA) was not only appropriate but required by the law. The statutory language that Congress used in Section 1557 is extremely broad, covering "*any* health program or activity." Health insurers clearly have a significant role in the provision of health care, including controlling access to health care services through benefit design, utilization management, and other means. Moreover, the *primary purpose* of the Affordable Care Act was to expand the availability and scope of health insurance and assist individuals in securing and enrolling in health insurance coverage. Further, the debate about the non-discrimination provisions during passage of the Affordable Care Act was about discrimination in insurance. If Congress meant to exclude health insurance from the term "health program or activity"—particularly in a law that is *about* health insurance—certainly Congress would have said so. Thus, the 2016 final rule's definition of "health program or activity" to mean "the provision or administration of health-related services, health-related insurance coverage, or other health-related coverage, and the provision of assistance to individuals in obtaining

[9] 84 Fed. Reg. 27846, 27850 (June 14, 2019) (applying the CRRA's definition of a "program or activity" receiving federal financial assistance for purposes of Section 504 of the Rehabilitation Act, Title VI of the Civil Rights Act of 1964, Title IX of the Education Amendments of 1972, and the Age Discrimination in Employment Act, which defined "program or activity" to cover "all operations of . . . an entire corporation, partnership, or other private organization, or an entire sole proprietorship (I) if assistance is extended to such corporation, partnership, private organization, or sole proprietorship as a whole; or (II) which is principally engaged in the business of providing . . . health care. . . ." to conclude that a "health program or activity" under Section 1557 cannot cover health insurers unless they receive federal financial assistance as a whole).

[10] 42 U.S.C. § 18116(a).

health-related services or health-related coverage"[11] reflects the clear language and intent of the law.[12]

HHS newly re-interprets "health program or activity," concluding that an entity "principally or otherwise engaged in the business of providing health insurance shall not, by virtue of such provision, be considered to be principally engaged in the business of providing health care."[13] It further states that federal financial assistance to *any part* of such an entity is not sufficient to trigger coverage of the entity under Section 1557, a conclusion entirely inconsistent with the statutory language of Section 1557.

The only justification that HHS offers for reading health insurance out of "health care" is a reference to another federal statute with an entirely different purpose (5 U.S.C. § 5371) that defines "health care" for purposes of that law as "direct patient-care services or services incident to direct patient care-services."[14] That law, however, concerns pay rates and personnel practices for federal employees, and uses the term "health care" simply to describe a category of federal employees who work in that sector. It would make little sense for that law to include individuals engaged in providing health insurance, as the federal government does not employ a large set of individuals to provide health insurance. Using an unrelated law with a different purpose to define health insurance largely out of the non-discrimination provisions of a law that is *about health insurance* is without foundation and inconsistent with the statute that HHS is interpreting.

B. Section 1557 Does Not Incorporate the CRRA

The proposed rule incorrectly attempts to incorporate the CRRA directly into Section 1557. Nothing in the text of the CRRA or that of Section 1557 supports such an incorporation. Moreover, the way that HHS proposes to incorporate the CRRA is inconsistent with the statutory language of Section 1557. The proposed rule incorporates language from the CRRA indicating that a program or activity of a private entity receiving federal financial assistance is covered by relevant laws (Section 504, Title VI, and Title IX) if the program or activity receives federal financial assistance "as a

[11] 45 C.F.R. § 92.4 (2016). The final rule further specified that for an entity "principally engaged in providing or administering health services or health insurance coverage or other health coverage" (including group health plans and health insurance issuers), all of its operations are considered part of the health program or activity except as otherwise specified in the rule. *Id*.
[12] HHS acknowledged in the final rule that there are concerns about excluding Medicare Part B from the definition of FFA. 81 Fed. Reg. 31384 (May 18, 2016). However, because HHS determined in final rule that the 1557 regulation was not the appropriate place for the government to change its position on this issue, we do not raise those concerns here.
[13] 84 Fed. Reg. 27846, 27891 (June 14, 2019).
[14] *Id. at* 27863.

whole" or if it is "principally engaged in the business of providing . . . health care . . ."). [15] Having defined health insurance out of "the business of providing health care," the proposed rule applies the CRRA to conclude that health insurers are covered by Section 1557 only to the extent that a particular operation receives federal financial assistance.

But Congress already *answered* the question of whether coverage under Section 1557 requires FFA for part of a program or activity or for its operations as a whole: it specifically stated in the statute that any health program or activity is covered if "any part" of it receives FFA. [16] The proposed rule ignores that language, which cannot be squared with HHS' new interpretation of the law. There is no logical way to read Section 1557's statutory language consistently with the language that HHS reads into Section 1557.

C. *HHS seeks to exempt itself and other federal programs and agencies from Section 1557's nondiscrimination requirements*

We have serious concerns about proposed changes that narrow the scope of the rule. The standards established under Section 1557 should apply to HHS health programs, as well as to health programs that receive FFA from HHS. This includes a range of important HHS activities, including, for example, programs administered by the Health Resources and Services Administration (HRSA) to improve health care for people who are geographically isolated, economically or medically vulnerable, and to support the health care workforce. The proposed rule, as formulated, including the scope of application in the new § 92.3(a), unnecessarily narrows and limits the departmental entities that are covered. This theory stands contrary to the statutory text, design, and intent of Section 1557 and the ACA as a whole.

As HHS stated when it originally proposed the rule in 2015, "a fundamental purpose of the ACA is to ensure that vital health care services are broadly and nondiscriminatorily available to individuals throughout the country." [17] Particularly given the context that people with disabilities have been and continue to be systemically disadvantaged by a health system with fragmented funding and delivery, an institutional bias in the provision of long-term services and supports (that many people with disabilities rely on to live, work, attend school and participate in their communities), and a long history of exclusion of people with disabilities from research and clinical trials, to name just a few troubling

[15] *Id. at* 27862 (Proposed § 92.3).
[16] 42 U.S.C. § 18116(a).
[17] 80 Fed. Reg. 54172 (Sept. 8, 2015).

issues in a history of unequal treatment, the interpretation of the application the rule to HHS programs must not be narrowed.

The plain language of Section 1557, as well as the 2016 Final Rule, establishes that any health "program or activity" administered by an Executive agency is subject to the law's provisions.[18] HHS' new interpretation of Section 1557 in effect changes the word "or" to "and," specifying that the law applies to health programs or activities administered by an Executive agency "and" created under Title I.[19] This reading is inconsistent with the statute, which includes the word "or", thereby plainly prohibiting discrimination by both programs or activities "administered by an Executive Agency" as well as those entities "established under" Title I of the ACA. If Congress had intended to limit Section 1557 only to those entities created under Title I, it would not have included the clause pertaining to executive agencies.

Moreover, if implemented, the new definition would lead to a situation whereby recipients of FFA would be subject to non-discrimination requirements of Section 1557, but agencies administering them would be exempt. For example, under HHS new interpretation, state Medicaid programs would be subject to Section 1557 as recipients of FFA, but the Centers for Medicare & Medicaid Services, which administers these programs, would be exempt. Such an interpretation is not only inconsistent with the plain meaning of Section 1557, but it is also inconsistent with Section 504, and therefore likely to cause significant confusion. HHS and all its components, including CMS, HRSA, CDC, SAMHSA, are subject to Section 504's prohibition on discrimination.[20]

RECOMMENDATION: HHS should retain the current regulations addressing the applicability of Section 1557 and not finalize the proposed 45 C.F.R. § 92.2 and 92.3.

II. The NPRM Deletes or Substantially Weakens Sections of the Regulations Prohibiting Discrimination against People with Disabilities.

The NPRM deletes several sections of the 2016 Final Regulation that are integral to implementing Section 1557's prohibition on discrimination against people with disabilities. CCD opposes HHS' proposal to repeal the current regulations, including:

- Definitions (§ 92.4);

[18] 42 U.S.C. § 18116(a); 45 C.F.R. §§ 92.1, 92.2, 92.4 (2016).
[19] 84 Fed. Reg. 27862 (June 14, 2019).
[20] 29 U.S.C. § 794; 45 C.F.R. Part 85.

- Designation of responsible employee and adoption of grievance procedures (§ 92.7);
- Notice Requirement (§ 92.8);
- Discrimination Prohibited (45 C.F.R. § 92.101);
- Nondiscrimination in Health Related Insurance and Other Health-Related Coverage (§ 92.207); and
- Nondiscrimination on the Basis of Association (§92.209);

We also object to HHS' proposal to delete the section entitled "Enforcement Mechanisms" (§ 92.301) and replace it with proposed § 92.5, as the proposed provision fails to recognize a private right of action and the availability of compensatory damages.

A. Proposed Repeal of "Definitions" (§ 92.4)

HHS proposed to delete the entire section of the Final Regulations that contains definitions for the regulation. We strongly oppose these changes. HHS contends that the "proposed rule retains most of the disability-rights related definitions from the current rule either explicitly . . . by using the definition to describing the requirements or characteristics of the entity; or by referencing underlying regulations or statutes, such as for technical accessibility standards and definitions."[21] As we note in Section III(A) below, the text of the NPRM demonstrates that HHS has altered crucial definitions related to effective communication, without any explanation or even acknowledgement that it is doing so. We urge HHS to retain all current definitions in § 92.4

RECOMMENDATION: HHS should retain the full definitions as articulated in 45 C.F.R. § 92.4.

B. Proposed Repeal of "Designation of Responsible Employee and Adoption of Grievance Procedures" (§ 92.7)

We oppose the deletion of requirements related to designation of a responsible employee and adoption of grievance procedures. The requirements for a responsible employee and adoption of a grievance procedure are very important to holding covered entities responsible for the protections provided by Section 1557. Without a designated employee and defined grievance procedure, many individuals protected by Section 1557 may not receive the information needed to prevent discrimination or seek redress for discrimination faced. Other federal civil rights laws require designation of a responsible employee and creation of grievance procedures; retaining the regulatory

[21] 84 Fed. Reg. 27860 (June 14, 2019).

grievance procedure for Section 1557 should not create a significant burden on covered entities.

RECOMMENDATION: HHS should retain § 92.7 in its entirety.

C. Proposed Repeal of "Notice Requirement" (§ 92.8)

We strongly support the notice and tagline requirements in current regulations that ensure covered entities inform beneficiaries, enrollees, applicants, and members of the public of the availability of language services and auxiliary aids and services, and that the entity does not discriminate on the basis of race, color, national origin, sex, age or disability. The proposed changes are inconsistent with Section 1557 and should not be finalized.

The 2016 Final Rule requires notice of the following:

(1) The covered entity does not discriminate on the basis covered by Section 1557;
(2) The covered entity provides auxiliary aids and services for people with disabilities;
(3) The covered entity provides language assistance services for individuals with LEP;
(4) How to obtain auxiliary aids and services;
(5) How to obtain language services;
(6) The availability of the grievance procedure; and
(7) How to file a discrimination complaint with OCR.[22]

First, the proposed elimination of notices compromises and diminishes the primacy of the non-discrimination message of Section 1557. To clearly communicate a covered entity's non-discrimination obligations and individuals' right to access services, a notice must be posted in physical locations, on websites, and sent with significant documents as the current regulations provide. If an individual enters an emergency department, for example, he or she needs to know immediately how to obtain auxiliary aids and services, or his or her medical care, health, and even life may be compromised. Similarly, if an individual cannot communicate with their insurance provider to obtain information regarding how to access covered services or benefits, they may suffer serious harm and be forced to forgo necessary care.

Second, the notice requirements under Section 1557 are not duplicative of any other requirements, especially Section 504 or Title VI. The notice requirements in the current

[22] 45 C.F.R. § 92.8 (2016).

regulations are explicit and designed to adequately inform individuals of the scope of their rights under Section 1557. By not fully explaining why repeal of the notices is necessary, HHS fails to justify the repeal. Further, HHS recognizes that eliminating the notice requirement will result in some individuals not knowing of their rights and how to enforce them. As HHS noted, "repealing the notice of nondiscrimination requirement may result in additional societal costs, such as decreased utilization of auxiliary aids and services by individuals with disabilities."[23] Any burdens of wall space and use of information technology staff and resources to post the notice and include it on a website are greatly outweighed by the benefit of having the notice visible and conspicuous so that individuals may access the services promised by Section 1557 as outlined in the notice.

While we recognize that some covered entities have raised concern about how often they have to send this notice with significant documents, the wholesale elimination of the notice is not justified by these concerns. Rather, HHS could consider a variety of options including an explanation of what constitutes significant documents or how often a covered entity has to send a notice if the covered entity sends multiple significant documents to individuals over the course of a year. Indeed, in comments submitted by insurers and medical associations in response to the original NPRM, the overriding question was about the frequency of sending notices or taglines rather than the need to send them at all.

HHS also fails to calculate the specific costs related to posting notices, and focuses almost entirely on the cost associated with mailings. Similarly, HHS's analysis does not separate out costs for providing notice of nondiscrimination versus the costs related to taglines in other languages, thereby making it impossible to appropriately understand which costs are related to providing notice in English, and which costs are related to taglines. Further, HHS failed to explain why completely eliminating notice requirements is justified given the prior analysis HHS has already undertaken in adopting these requirements just a few short years ago. We thus oppose the repeal of requirements related to notices.

RECOMMENDATION: HHS should retain § 92.8 in its entirety.

D. Proposed Repeal of "Discrimination Prohibited" (§ 92.101)

HHS proposes to delete § 92.101 of the current rule, claiming it will be replaced by "provisions addressing Section 1557's purpose, nondiscrimination requirements, scope of application, enforcement mechanisms, relationship to other laws, and meaningful

[23] 84 Fed. Reg. 27846, 27883 (June 14, 2019).

access for LEP individuals."[24] However, § 92.101 contains important prohibitions on discrimination that the recent NPRM fails to incorporate.

By deleting 92.101(b)(2), HHS deletes references to important regulatory definitions of disability discrimination. For example, the current regulation states that "Each recipient and State-based Marketplace[SM] must comply with the regulation implementing Section 504, at §§ 84.4(b), 84.21 through 84.23(b), 84.31, 84.34, 84.37, 84.38, and 84.41 through 84.52(c) and 84.53 through 84.55 of this subchapter."[25] It also states that "[t]he Department, including the Federally-facilitated Marketplaces, must comply with the regulation implementing Section 504, at §§ 85.21(b), 85.41 through 85.42, and 85.44 through 85.51 of this subchapter."[26] These cross-references clarify that covered entities have an affirmative obligation to ensure that their health care is accessible to individuals with disabilities in myriad ways not captured in other sections of the NPRM.

For example, §§ 84.4(b) and 85.21(b) prohibit discrimination by:

- denying individuals with disabilities the opportunity to participate;
- affording unequal opportunity to participate;
- providing a less effective aid, benefit or service;
- providing different or separate aids, benefits, or services; or
- otherwise limiting a person with a disability in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving an aid, benefit, or service.

The regulations also prohibit recipients from:

> utiliz[ing] criteria or methods of administration (i) that have the effect of subjecting qualified handicapped persons to discrimination on the basis of handicap, (ii) that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the recipient's program or activity with respect to handicapped persons, or (iii) that perpetuate the discrimination of another recipient if both recipients are subject to common administrative control or are agencies of the same State."[27]

[24] *Id.* at 27860.
[25] 45 C.F.R. § 92.101(b)(2)(i) (2016).
[26] 45 C.F.R. § 92.101(b)(2)(ii) (2016).
[27] 45 C.F.R. § 84.4(b) (2010); 45 C.F.R. § 85.21(b) (2003).

In short, without the inclusion of § 92.101, the NPRM's description of prohibited discrimination under Section 504, and thereby Section 1557, is incomplete.

RECOMMENDATION: HHS should retain § 92.101 in its entirety.

E. Proposed Repeal of "Nondiscrimination in Health-Related Insurance and Other Health-Related Coverage (§ 92.207)

CCD strongly opposes HHS' proposal to eliminate 45 C.F.R. § 92.207, a regulation that specifies that Section 1557 prohibits covered entities from discriminating in the issuance or renewal of a health insurance policy, the coverage of a health insurance claim, cost-sharing and other coverage limitations, marketing practices, and the design of the health benefit plan. HHS' proposal to repeal this entire regulation is contrary to the text and purposes of the ACA; it would disproportionately harm people with disabilities; and it is inadequately justified in the NPRM.

In enacting the ACA, Congress intended to prohibit health insurance practices, including plan benefit designs, that discriminate on the basis of race, color, national origin, sex, age, or disability. The ACA significantly changed the health insurance industry by not only expanding access to health coverage, but also explicitly prohibiting many of the methods historically used by health insurers to minimize costs and risks. Before the ACA, the business model of health care incentivized insurers to avoid covering individuals who had high health needs or who would otherwise be costly to the plan. While there was some federal and state regulation of restrictive coverage policies, insurers still had a large array of mechanisms at their disposal to deny enrollment, limit benefits, and impose high premiums and cost-sharing on enrollees with disabilities and pre-existing conditions.[28] The ACA ushered in a new era for health care equity—implementing reforms to expand coverage; create protections in enrollment, cost-sharing, and benefit coverage; and improve the scope and quality of health insurance.

As an integral component of these reforms, Congress mandated comprehensive health benefit coverage and explicitly prohibited discriminatory practices in the content of those plan designs. Most pertinent, it prohibited limitations or exclusions of benefits based on pre-existing conditions; it mandated coverage, on a nondiscriminatory basis, of ten

[28] *See, e.g.*, Valarie K. Blake, *An Opening for Civil Rights in Health Insurance After the Affordable Care Act*, 36 B.C. J. L. & SOC. JUST. 235 (2016) (describing pre-ACA health insurance discrimination and how the ACA addressed those issues); Sara Rosenbaum et al., *Crossing the Rubicon: The Impact of the Affordable Care Act on the Content of Insurance Coverage for Persons with Disabilities*, 25 NOTRE DAME J. L. ETHICS & PUB. POL'Y 235 (2014) (describing ACA nondiscrimination provisions and focusing on the function of essential health benefits).

categories of essential health benefits (EHBs); and it prohibited qualified health plan (QHP) "marketing practices or benefit designs that have the effect of discouraging the enrollment in such plan by individuals with significant health needs," among other protections.[29]

Section 1557 of the ACA is the key to enforcing these statutory mandates. Section 1557 prohibits discrimination, including discrimination in the design of a benefit package, in health programs or activities receiving federal financial assistance, under any program or activity that is administered by an Executive Agency, or by any entity established under Title I of the ACA.[30] By statute, it creates a private right of action for individuals to enforce their civil rights in the health care context.[31] The scope of actionable discrimination under Section 1557 logically covers discrimination in enrollment, equal access to benefits, and benefit design.[32]

Recognizing this statutory requirement, HHS promulgated regulations in 2016 reiterating that Section 1557 prohibits "marketing practices or benefit designs that discriminate on the basis of race, color, national origin, sex, age, or disability in a health-related insurance plan or policy."[33] In guidance, it provided examples of practices that would contravene Section 1557 and this regulation. Plans that, for example, "cover bariatric surgery in adults but exclude such coverage for adults with particular developmental disabilities;"[34] "plac[e] most or all drugs that treat a specific condition on the highest cost tiers;"[35] or "exclude bone marrow transplants regardless of medical necessity"[36] would run afoul of Section 1557, it explained.

HHS' 2016 regulation logically follows the letter and intent of the ACA. Explicit acknowledgement of, and a resulting prohibition on, discriminatory benefit design is critical to the effectiveness of Section 1557's nondiscrimination protections. If Section 1557 did not clearly reach the structure of a benefit package, a health insurer could

---

[29] 42 U.S.C. § 300gg-3(b)(1); 42 U.S.C. § 18022; 42 U.S.C. § 18031(c)(1)(A).
[30] *See* 42 U.S.C. § 18116(a).
[31] *See, e.g.*, *Rumble v. Fairview Health Servs.*, No. 14-cv-2037, 2015 WL 1197415 (D. Minn. Mar. 16, 2015) (finding that Section 1557 creates a private right of action).
[32] *See, e.g.*, The AIDS Inst. & Nat'l Health Law Program, *Administrative Complaint RE: Discriminatory Pharmacy Benefits Design in Select Qualified Health Plans Offered in Florida* (May 28, 2014), https://healthlaw.org/resource/nhelp-and-the-aids-institute-complaint-to-hhs-re-hiv-aids-discrimination-by-fl/ (HHS OCR complaint alleging that placing all HIV/AIDS medications in the highest cost-sharing tier violates Section 1557).
[33] 45 C.F.R. § 92.207 (2016).
[34] 81 Fed. Reg. 31376, 31429 (May 18, 2016).
[35] 80 Fed. Reg. 10750, 10822 (Feb. 17, 2015).
[36] *See* CMS CCIIO, *QHP Master Review Tools for 2015, Non-Discrimination in Benefit Design* (2015), http://insurance.ohio.gov/Company/Documents/2015_Non-Discriminatory_Benefit_Design_QHP_Standards.pdf.

always manipulate their benefit design to elude discrimination law, despite maintaining the same discriminatory effects. For illustration, consider cancer benefits. If discrimination in benefit designs were permitted, a health insurer could exclude from its coverage all cancer-related surgery, chemotherapy, radiation, and post-treatment drugs, even if it could not deny an individual with cancer enrollment in a QHP or equal access to the treatments, services, and prescription drugs the plan chooses to cover. It could also limit beneficiaries to provider networks that fail to include key oncology specialists, thus avoiding coverage of the expensive treatments they may prescribe. For a person with cancer, access to a health plan would be deemed virtually meaningless in the absence of cancer-related coverage. The effect of these exclusions would be the same as an outright denial of enrollment. Elimination of the benefit design regulation perversely encourages this result. It incentivizes insurers to find roundabout ways to deter people with pre-existing conditions from their plans. This is impermissible under Section 1557 of the ACA as well as Section 504 of the Rehabilitation Act.[37]

The elimination of the benefit design regulation will disproportionately harm people with disabilities, who rely on Section 1557's enforcement mechanisms to hold health insurers and health providers accountable for discriminatory practices. People with disabilities already experience significant disparities in health outcomes and access to health care.[38] For example, adults with disabilities are 58% more likely to experience obesity, three times more likely to be diagnosed with diabetes, and nearly four times more likely to have early-onset cardiovascular disease.[39] Moreover, they are nearly three times more likely to have not accessed needed health care because of cost and twice as likely to have unmet mental health needs.[40] The ACA's reforms worked to reduce some of these disparities by, for example, reducing the uninsurance rate and increasing the likelihood of a person with a disability having a regular health care provider.[41] However, there are still large gaps in health access and persistent attitudinal and programmatic barriers to care are ongoing.[42] Section 1557 provides an avenue through which people

---

[37] See 29 U.S.C. § 794; 42 U.S.C. §§ 18116(a), 18031(c)(1)(A); 45 C.F.R. § 92.207(b)(2) (2016).

[38] *See, e.g.*, Silvia Yee et al., *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity*, NAT'L ACADS. SCI., ENG'G, & MED. 1 (2017), *available at:* http://nationalacademies.org/hmd/Activities/SelectPops/HealthDisparities/Commissioned-Papers/Compounded-Disparities.

[39] *Id.* at 32.

[40] *Id.* at 31.

[41] *See* H. Stephen Kaye, *Disability-Related Disparities in Access to Health Care Before (2008–2010) and After (2015–2017) the Affordable Care Act*, 109:7 AM. J. PUB. HEALTH 1015–21 (2019); Gloria L. Krahn, *Drilling Deeper on the Impact of the Affordable Care Act on Disability-Related Health Care Access Disparities*, 109:7 AM. J. PUB. HEALTH 956–58 (2019).

[42] *See* Kaye, *supra* note 41, at 1019–21 (for example, across the population of people with disabilities, there has been "much greater delayed or forgone care" post-ACA); Yee, et al., *supra* note 38, at 31–32; 39–44.

with disabilities can identify and challenge discriminatory policies—including those that manifest in the design of a health plan's benefit package. Elimination of the benefit design protections will allow health insurers to perpetuate coverage policies that exclude people with certain disabilities from benefit coverage or target the health care services, devices, and prescription drugs that people with disabilities disproportionately rely on. As a group of individuals already facing significant external barriers in the health care context, such a regression of their civil rights should not be realized.

Finally, HHS has not provided sufficient explanation on *why* it proposes to eliminate the benefit design regulation in the NPRM. The only reference to the current regulation is in Footnote 147, wherein the referenced text states that a handful of the current Section 1557 regulations are "duplicative of, inconsistent with, or confusing in relation to" pre-existing Section 504, Title VI, Title IX, and Age Act regulations.[43] It is unclear which of these three factors HHS is relying on with respect to the benefit design regulation. Regardless, concerns of duplication, inconsistency, or confusion in this context are unfounded. First, the benefit design regulation does not duplicate existing regulations. Section 1557 practically applies longstanding civil rights principles to the unique context of health care. Because pre-existing statutes such as Section 504 are more generally applicable and have not historically been applied to private health insurers,[44] their regulations do not explain how the content of a health benefit package can discriminate.[45] Thus, it was necessary to explain this concept in the Section 1557 regulations. Second, the benefit design regulation is also not inconsistent with or confusing in relation to pre-existing civil rights regulations. Its provisions do not contradict currently-existing regulations. Instead—in recognition that the ACA significantly reformed the health insurance market, increased administrative oversight of health plans, and applied nondiscrimination principles to private health insurers for the first time—the Section 1557 benefit design regulation served to explain one form of health insurer discrimination that was previously difficult to challenge.[46] The regulation should not be repealed on these erroneous grounds.

---

[43] 84 Fed. Reg. 27846, 27869 (June 14, 2019).

[44] Prior to the ACA, most private health insurance plans that did not receive federal financial assistance, and thus Section 1557 and Title VI did not typically apply to them. The ACA's creation of, e.g., premium tax credits and federal- and state-run exchanges, changed this.

[45] *See, e.g.*, 28 C.F.R. § 41 (2019) (HHS Section 504 regulations).

[46] Prior to the ACA, private health insurers were generally not subject to disability nondiscrimination laws. Additionally, some lower courts misinterpreted the U.S. Supreme Court's decision in *Alexander v. Choate*, 469 U.S. 287 (1985) to stand for the proposition that Section 504 does not reach the "content" of a health benefit policy, but rather only the ability to "access" the benefit. *See, e.g.*, Doe v. Mutual of Omaha Ins. Co., 179 F.3d 557 (7th Cir. 1999). These erroneous interpretations of *Choate* critically misunderstood the Supreme Court's holding, which made clear that people with disabilities must have "meaningful access" to health care benefits. 469 U.S. at 296–99, 301. The benefit, it explained, could not be defined in a way

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.207 in its entirety.

F. Proposed Repeal of "Nondiscrimination on the Basis of Association" (§ 92.209)

Current regulations expressly prohibit discrimination on the basis of association with a protected class. Without explanation, the NPRM eliminates this provision. Congress intended Section 1557 to protect against discrimination by association, and these provisions should be retained.

In the 2016 Final Rule, HHS explains that the statute does not restrict

> the prohibition to discrimination based on the individual's own race, color, national origin, age, disability or sex. Further, we noted that a prohibition on associational discrimination is consistent with longstanding interpretations of existing antidiscrimination laws, whether the basis of discrimination is a characteristic of the harmed individual or an individual who is associated with the harmed individual.[47]

The current regulation's language tracks statutory language of Title I and Title III of the ADA, and the regulatory language of Title II of the ADA, which protect against discrimination based on association or relationship with a person with a disability.[48] Congress intended that Section 1557 provide at least the same protections for patients and provider entities. In accord with the ADA, the current regulation recognizes this protection extends to providers and caregivers, who are at risk of associational discrimination due to their professional relationships with patients, including those patient classes protected under Section 1557. For example, a dentist may not refuse to treat an HIV-positive individual based on unfounded fears of transmission. Similarly, the individual's HIV-negative partner would also be protected under Section 1557, if the dentist refused to treat her based on her relationship with an HIV-positive individual.

---

that disparately harms people with disabilities. *Id.* For further analysis of the meaning of *Alexander v. Choate* in the context of ACA-regulated health plans, *see* Brief of Disability Rights Education and Defense Fund, Disability Rights Advocates, Disability Rights California, Disability Rights Legal Center, The National Health Law Program, and The American Civil Liberties Union as *Amici Curiae* in Support of Neither Party, *Doe One v. CVS Pharmacy, Inc.*, No. 19-15074 (9th Cir. appeal filed Jan. 1, 2019), https://dredf.org/2019/07/02/doe-v-cvs-pharmacy-inc/.

[47] 81 Fed. Reg. 31376, 31439 (May 18, 2016).

[48] 42 U.S.C. 12112(b)(4)(Title I); 42 U.S.C. 12182(b)(1)(E)(Title III); 28 C.F.R. 35.130(g)(Title II) (2010).

By eliminating regulatory provisions expressly prohibiting discrimination on the basis of association, HHS will create uncertainty and confusion regarding the responsibilities of providers and the rights of persons who experience discrimination. However, because HHS provides no explanation of its reasons for removing 45 C.F.R. § 92.209, we cannot adequately comment, and urge HHS to retain the current regulatory protections.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.209 in its entirety.

G. Proposed Modification of "Enforcement Mechanisms" (§ 92.301; Proposed § 92.5)

We oppose the proposed changes to § 92.301 as newly designated § 92.5. HHS's NPRM incorrectly attempts to limit the remedies available under Section 1557. Congress intentionally designed Section 1557 to build and expand on prior civil rights laws such that individuals seeking to enforce their rights would have access to the full range of available civil rights remedies and not be limited to only the remedies provided to a particular protected group under prior civil rights laws. Section 1557 expressly provides individuals access to any and all of the "rights, remedies, procedures, or legal standards available" under the cited civil rights statutes, regardless of the type of discrimination. Rather than recognizing that the statute creates a single standard for addressing health care discrimination, HHS's interpretation of the statute in these regulations as amended and re-designated would instead attempt to create multiple piecemeal legal standards and burdens of proof derived from different statutory contexts. HHS's interpretation is contrary to the statutory language and Congress's intent.

The proposed language is not a valid interpretation of Section 1557. While the statute expressly sets out the grounds for discrimination by reference to the cited civil rights statutes, it does not set forth separate remedies, legal standards, and burdens of proof applicable to each prohibited basis of discrimination based on the statutes that are referenced.[49] To the contrary, Congress specified that "[t]he enforcement mechanisms provided for and available under such Title VI, Title IX, Section 504, *or* such Age Discrimination Act shall apply for purposes of violations of this subsection."[50] The use of the disjunctive "or" indicates that any of the enforcement mechanisms applicable under any of the incorporated statutes are available to every claim of discrimination under Section 1557, regardless of the particular type of discrimination triggering the claim.

---

[49] *See* Sarah G. Steege, *Finding A Cure in the Courts: A Private Right of Action for Disparate Impact in Health Care*, 16 MICH. J. RACE & L. 439, 462 (2011) ("[T]here is no indication in § 1557 that each listed statute's enforcement mechanisms apply only to its own protected classes.").
[50] 42 U.S.C. § 18116(a) (emphasis added).

Applying standard rules of construction, all the enforcement mechanisms provided for and available under each of the generally incorporated statutes in Section 1557 are available to every claim of discrimination under Section 1557.

It is also necessary to read Section 1557 as establishing a single standard for addressing health care discrimination to avoid "patently absurd consequences."[51] HHS's reading of Section 1557 in this proposed section "would lead to an illogical result, as different enforcement mechanisms and standards would apply to a Section 1557 plaintiff depending on whether the plaintiff's claim is based on her race, sex, age, or disability."[52] Moreover, courts would be left without guidance on how to address intersectional claims—should a person who alleges discrimination on the basis of both race and age be subject to the standards and enforcement mechanisms under a Title VI analysis or the Age Discrimination Act? Congress explicitly adopted one provision to prohibit all discrimination in health care. It strains the imagination to read that one provision would require agencies and courts to apply a hodgepodge of standards and enforcement mechanisms.

Further, the proposed changes to the regulation do not comport with congressional intent. Congress did not intend that the enforcement mechanisms and standards available under 1557 be tethered to the nature of the claim. Rather, in enacting 1557, Congress sought to "create a new right and remedy in a new context without altering existing laws."[53] Congress has repeatedly expressed that it intends civil rights laws to be broadly interpreted in order to effectuate their remedial purposes.[54] By trying to narrowly limit the legal standards and burdens of proof that apply to those who have experienced health care discrimination, HHS's interpretation in the NPRM would ignore Congress's intent to provide broad remedies to address discrimination. HHS should not finalize the proposed language in § 92.5.

As HHS notes, some courts have interpreted Section 1557 to apply different enforcement mechanisms and standards depending on whether someone's claim is based on race/ethnicity/national origin, sex, age, or disability. These courts rely on the fact that Congress incorporated the enforcement mechanisms from the four cited civil rights statutes to then incorrectly conclude that Section 1557 limits the standards and enforcement mechanisms available based on the statute that defines the grounds for

[51] *United States v. Brown*, 333 U.S. 18, 27 (1948).
[52] *Rumble*, 2015 WL 1197415, at *11 (D. Minn. Mar. 16, 2015).
[53] *See id.* at *11, note 6.
[54] *See Kang v. U. Lim Am., Inc.*, 296 F.3d 810, 816 (9th Cir. 2002); *see also* H.R. Rep. No. 102–40(I), at 88, U.S. Code Cong. & Admin. News at 626 (stating that "remedial statutes, such as civil rights law[s], are to be broadly construed").

discrimination.[55] But the courts in these cases miscomprehend the statutory language and context. As discussed above, Section 1557 expressly provides for broad and uniform enforcement, consistent with Congress's intent that civil rights laws provide broad remedies. While Congress could perhaps have more clearly articulated its intent to establish a single statutory standard for determining discrimination and enforcing Section 1557, its failure to perfectly articulate such a standard does not necessitate the narrow reading of the statute articulated in the NPRM and the cases it cites.[56] These cases overly rely on interpretations of the underlying statutes without recognizing the inherent shifts that ACA made in the health care realm.[57]

We particularly oppose HHS's proposal to replace current § 92.301(b) with proposed § 92.5(b). Every court that has ruled on the question has found that the statutory language of Section 1557 confers a private right of action for monetary damages. The existence of such a right is clear from the statutory language in Section 1557, which explicitly references and incorporates the "enforcement mechanisms" of the four civil rights laws listed—all of which contain a private right of action. Once again, this understanding is also consistent with Congress's intent that civil rights laws be broadly interpreted to effectuate the remedial purposes of those laws. Removing the regulatory language that makes clear that private right of action and monetary damages are available to redress violations of Section 1557 will serve only to confuse. HHS should not finalize proposed § 92.5(b).

RECOMMENDATION: HHS should retain § 92.301 in its entirety.

III. Requests for Comment

Throughout the NPRM, HHS requests comments on numerous provisions, many of which would be more appropriate to inform agency decisions prior to issuing an NPRM,

---

[55] *See, e.g., Southeastern Pennsylvania v. Gilead*, 102 F. Supp. 3d 688, 699 n.3 (E.D. Pa. 2015); *Briscoe v. Health Care Serv. Corp*., 281 F. Supp. 3d 725, 738 (N.D. Ill. 2017); *see also, e.g., Doe v. BlueCross BlueShield of Tennessee, Inc*., 926 F.3d 235, 241 (6th Cir. 2019).

[56] *See King v. Burwell*, 135 S. Ct. 2480, 2492 (2015) (noting that the ACA "contains more than a few examples of inartful drafting" and thus emphasizing the importance of considering the broader context of the statute).

[57] The Supreme Court has recognized that the broader purpose of the ACA is to "expand insurance coverage…[and] ensure that anyone can buy insurance." *King*, 135 S. Ct. at 2493. An expansive prohibition on discrimination in health care is key to ensuring that *anyone* can buy insurance. Thus other courts have properly concluded that a single standard and burden of proof apply under Section 1557: "looking at Section 1557 and the Affordable Care Act as a whole, it appears that Congress intended to create a new, health-specific, anti-discrimination cause of action that is subject to a singular standard, regardless of a plaintiff's protected class status." *Rumble*, 2015 WL 1197415, at *10.

such as through a Request for Information, than in response to an NPRM. However, where HHS proposes specific disability-related questions, we have responded below.

A. "Effective Communication for Individuals with Disabilities" (§ 92.202; Proposed § 92.102)

CCD supports HHS' proposal to retain the provisions of 45 C.F.R. § 92.202 (redesignated § 92.102), regarding effective communication for individuals with disabilities. Effective communication is a critical component of accessing and receiving quality health care. We often hear about entities refusing to provide effective communication or relying on communication methods that are the preference of the entity rather than the choice of the individual. Therefore, we commend HHS for holding all covered entities to the higher ADA Title II standards found at 28 C.F.R. §§ 35.160–35.164. Giving primary consideration to the choice of aid or service requested by the individual with a disability helps to ensure actual effective communication and thus equal opportunity in the health care setting.

We are, however, concerned with HHS' proposed changes to the definitions relating to the effective communication regulation. First, we object generally to the deletion of the definitions section at 45 C.F.R. § 92.4. The elimination of this section will cause confusion for covered entities and risk inconsistency among the various Section 1557 regulations. It also makes it more difficult to amend definitions as needed, which is especially important in the context of effective communication, as auxiliary aid technologies are constantly evolving. Second, while we appreciate HHS' efforts to incorporate many of the current ADA definitions, including the definitions of disability, auxiliary aids and services, qualified interpreter, and video remote interpreting, we note that HHS has erred in tracking the language of these longstanding definitions. The problems we have identified are as follows:

- The definition of auxiliary aids and services at proposed § 92.102(b)(1) excludes "acquisition or modification of equipment and devices" and "[o]ther similar services and actions," despite these two items being found in the ADA definition at 28 C.F.R. § 35.104 and the current Section 1557 definition at 45 C.F.R. § 92.4. HHS states in its NPRM that "[t]he list of auxiliary aids and services from 28 CFR 35.104 is incorporated into the proposed rule at § 92.102(b)(1)" and in general that "[t]hese provisions are drawn from regulations implementing Title II of the Americans with Disabilities."[58] This list is incomplete and HHS' statements are misleading. Parts of 28 C.F.R. § 35.104 are incorporated into the NPRM, but the above-quoted language regarding the "acquisition or modification of equipment

[58] 84 Fed. Reg. 27846, 27867, n. 123 (June 14, 2019).

and devices" and "other similar services and actions" is missing. This deletion alters what was an open-ended functional definition, and takes what is clearly a list of examples of auxiliary aids and services in the current regulations and turns it into an exhaustive list in the proposed regulation. Moreover, to the extent that HHS claims it seeks to eliminate inconsistent applications of the law, such change is neither prudent nor consistent with the law. We strongly oppose these deletions.

- The definition of auxiliary aids and services at proposed § 92.102(b)(1) also excludes the term "Qualified" before "Interpreters" in subsection (i) and before "Readers" in subsection (ii), despite this critical adjective being found in the ADA definition at 28 C.F.R. § 35.104 and the current Section 1557 definition at 45 C.F.R. § 92.4. While we appreciate that HHS does track the content of the ADA definition of *qualified* interpreters at proposed § 92.102(b)(2)–(3), we believe it will enable greater clarity and consistency with the ADA regulations to keep the term "Qualified interpreters" in the auxiliary aids definition at proposed § 92.102(b)(1)(i). Moreover, the word "Qualified" has also been deleted from "readers" in proposed § 92.102(b)(1)(ii), yet the proposal fails to incorporate the ADA definition of qualified readers. We strongly encourage HHS to both include the word "Qualified" in proposed § 92.102(b)(1)(ii), and incorporate the ADA definition of this term, *see* 28 C.F.R. § 351.04 ("Qualified reader means a person who is able to read effectively, accurately, and impartially using any necessary specialized vocabulary."). The change here is not merely theoretical. Covered entities should not, for example, be free to assign the task of reading personal information about health care status, medical procedures, and bills to a high school student hired to help with receptionist duties over the summer. The requirement for a defined "qualified reader" helps to ensure effective communication and health care for people with disabilities.

CCD is also concerned with the narrowing of the "free of charge" and "timely manner" provision at proposed § 92.102(b)(2). The current Section 1557 regulations provide that a covered entity must provide appropriate auxiliary aids and services, including qualified interpreters for individuals with disabilities and information in alternate formats, free of charge and in a timely manner . . ."[59] This language echoes the ADA Title II regulations, which provide that covered entities "may not place a surcharge on a particular individual with a disability or any group of individuals with disabilities to cover the costs of measures, such as the provision of auxiliary aids or program accessibility . . . "[60] In proposed § 92.102(b)(2), HHS significantly narrows this provision by only stating that

[59] 45 C.F.R. § 92.8 (2016).
[60] 28 C.F.R. § 35.130(f) (2010).

"*interpreting service* shall be provided to individuals free of charge and in a timely manner" (emphasis added).[61] We strongly oppose this change and encourage HHS to replace the words "interpreting service" with "auxiliary aids and services" to be consistent with the ADA and prevent unnecessary confusion over the requirement. Covered health care entities may not legally charge for *any* auxiliary aid provided; this pre-existing legal requirement should be made clear.

Finally, HHS requests comment on whether it should add an exemption from the effective communication requirements for covered entities with fewer than 15 employees.[62] CCD strongly opposes this exemption. HHS has not applied such an exemption in nearly 20 years and to apply it now would roll back the clock on the enforcement of effective communication for people with disabilities. To be clear, effective communication requirements profoundly impact threshold access to and the quality of health care that a person with a disability receives. Breakdowns in communication between a health care provider and a patient with a disability are reported across all types of disabilities,[63] and the lack of accurate and effective communication can lead to misdiagnosis, erroneous treatment, and ultimately a negative impact on the health of the patient.[64] The lack of positive health care communication experiences can also lead to a loss of trust or fear of health care providers, leading some people with disabilities to feel as if they have no choice but to rely upon self-diagnosis and treatment.[65] The provision of appropriate auxiliary aids and services can help remedy some of these health care disparities. For example, the provision of ASL interpreters to Deaf patients preferring this type of communication accommodation has been linked with significantly higher utilization rates of preventative care, including cholesterol screens, colonoscopy, and influenza vaccines.[66] While there are still many improvements to be made, requiring all covered entities to provide effective communication is a vital first step towards ensuring health care equity.

---

[61] 84 Fed. Reg. 27846, 27893 (June 14, 2019)
[62] *Id.* at 27867.
[63] *See, e.g.*, Thilo Kroll et al., *Primary Care Satisfaction Among Adults with Physical Disabilities: The Role of Patient-Provider Communication*, 11:1 MANAGED CARE Q. 11–19 (2003); Melinda Neri & Thilo Kroll, *Understanding the Consequences of Access Barriers to Health Care: Experiences of Adults with Disabilities*, 25:2 DISABILITY & REHAB. 85–96 (2003); Sara Bachman et al., *Provider Perceptions of Their Capacity to Offer Accessible Health Care For People With Disabilities,* 17:3 J. DISABILITY POL'Y STUD. 130–36 (2006); Elizabeth H. Morrison et al., *Primary Care for Adults with Physical Disabilities: Perceptions from Consumer and Provider Focus Groups*, 40:9 FAM MED. 645–51 (2008).
[64] *See* Yee, et al., *supra* note 38, at 43–44 (summarizing and analyzing the abundance of research on this point).
[65] *Id.*
[66] Michael M. McKee et al., *Impact of Communication on Preventive Services Among Deaf American Sign Language Users*, 41 AM. J. PREVENTATIVE MED., no. 1, 75–79 (2011).

Provider offices with fewer than 15 employees should not be exempted from this basic civil rights requirement. People with disabilities often obtain their health care from local providers or specialists with only a few employees. This is especially true in rural areas, where providers are more likely to have smaller practices, and there may only be one appropriate specialist within a reasonable distance. This exemption could thus function to exclude many people with disabilities from accessing the health care they need. The American Medical Association's (AMA's) Physician Practice Benchmark Survey in the period from 2012-16 found that a majority of physicians still work in small practices, with 57.8% in practices of 10 or fewer physicians, and 37.9% working in practices with fewer than 5 physicians in 2016.[67] Physicians in single specialty practices were even more likely to be in smaller practices. A practice with 10 physicians may or may not have 15 or fewer employees, but a practice with 5 physicians is very likely to have fewer than 15 employees. Exempting these small practices means that people with disabilities will have significantly more difficulty obtaining effective communication from both general and specialty physicians, and sends the message that HHS's latest health care-specific civil rights regulations make it harder for people with communication disabilities to obtain needed health care. Congress surely did not intend such a result in enacting the ACA and Section 1557.

Moreover, in practice, this exemption would make little sense because public accommodations (including hospitals and provider offices) of any size are already required to provide effective communication under Title III of the ADA. Even HHS, when it originally announced that the 15-employee exemption does not apply to entities receiving HHS funds, recognized this reality:

> This is not a new requirement; Title III of the Americans with Disabilities Act (ADA) already requires public accommodations of all sizes to provide auxiliary aids and services to persons with disabilities where necessary to ensure effective communication and Title II of the ADA extends the same requirement to state and local government entities. The vast majority of entities that receive federal financial assistance from HHS thus are already required to provide auxiliary aids and services to persons with disabilities where necessary to ensure effective communication.[68]

---

[67] *See* Carol K. Cane, *Updated Data on Physician Practice Arrangements: Physician Ownership Drops Below 50 Percent*, J. AM. MED. POLICY RESEARCH PERSPECTIVES (2017), *available at: https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/public/health-policy/PRP-2016-physician-benchmark-survey.pdf.* The Benchmark surveys are of practicing physicians who provide a minimum of 20 hours of patient care/week in one of the 50 states or the District of Columbia, and who are not employed by the federal government.

[68] 65 Fed. Reg. 79368 (Dec. 19, 2000).

If HHS intends to protect small entities from costs, then the appropriate mechanisms to do so is already in 45 C.F.R. § 92.202, which incorporates the ADA Title II exemptions found in 28 C.F.R. § 35.164 by explicit reference.[69] Adding an exemption for small entities will harm people with disabilities and is not the proper solution.

RECOMMENDATIONS:

- **HHS should clarify that the list of auxiliary aids and services in proposed § 92.102(b)(1) is not exhaustive by adding the following after subsection (ii):**

  "(iii) Acquisition or modification of equipment and devices; and

  (iv) Other similar services and actions."

- **HHS should restore the term "Qualified" before "Interpreters" in proposed § 92.102(b)(1)(i) and before "Readers" in proposed § 92.102(b)(1)(ii), and it should incorporate the definition of "Qualified readers" found at 28 C.F.R. § 35.104.**

- **The requirement to provide services "free of charge and in a timely manner" in proposed § 92.102(b)(2) should be applied to all "auxiliary aids and services," not just "interpreter services."**

- **No exemption should be added for covered entities with fewer than 15 employees.**

B. "Accessibility Standards for Buildings and Facilities" (§ 92.203, Proposed § 92.103)

CCD supports HHS' proposal to retain the provisions of 45 C.F.R. § 92.203 (redesignated § 92.103), regarding accessibility standards for buildings and facilities. We support HHS' position that the 2010 ADA Standards for Accessible Design ("2010

[69] 28 C.F.R. § 35.164 (2009) ("This subpart does not require a public entity to take any action that it can demonstrate would result in a fundamental alteration in the nature of a service, program, or activity or in undue financial and administrative burdens. In those circumstances where personnel of the public entity believe that the proposed action would fundamentally alter the service, program, or activity or would result in undue financial and administrative burdens, a public entity has the burden of proving that compliance with this subpart would result in such alteration or burdens.").

Standards") are the appropriate architectural standards for any facility or part of a facility in which health programs or activities are conducted that is constructed or altered by or on behalf of, or for the use of, a recipient or State Exchange. We appreciate HHS' continued commitment to ensuring that health care facilities and provider offices are physically accessible for people with disabilities.

HHS requests comment on the appropriateness of applying the 2010 ADA Standards' definition of "public building or facility" (i.e., the ADA Title II standards) to all entities covered under Section 1557, specifically with respect to multistory building elevators and text telephone ("TTY") requirements.[70] CCD believes that it is indeed appropriate and *necessary* to hold all health programs and activities that receive federal financial assistance to these higher Title II standards, and we strongly oppose importing the private multistory building exception found at Section 206.2.3 of the 2010 Standards and the private entity TTY standard found at Section 217.4.3 of the 2010 Standards into Section 1557.

First, by virtue of accepting federal financial assistance from HHS, it is entirely appropriate to hold <u>all</u> covered health programs and activities, including private entities, to the Title II standards. If we look at the ADA in a vacuum, a private entity that operates as a place of public accommodation would only be subject to the lower Title III architectural standards. However, here, the ADA standards function in relation to Section 1557, which notably references and incorporates the grounds of discrimination of Section 504, not the ADA. Section 504 covers programs and activities receiving federal financial assistance. So, in this context, some private health care practices, for example, would be on the hook for not only being a public accommodation under Title III, but also an entity that avails itself to nondiscrimination law (Section 504 and Section 1557) by virtue of choosing to accept federal financial assistance from HHS. This distinction justifies holding private health care entities to a higher standard, which even HHS itself recognized in its 2015 NPRM:

> [The] entities covered under the proposed rule are health programs and activities that either receive Federal financial assistance from HHS or are conducted directly by HHS. Although OCR could apply Title II standards to States and local entities and Title III standards to private entities, we believe it is appropriate to hold all recipients of Federal financial assistance from HHS to the higher Title II standards as a condition of their receipt of that assistance.[71]

[70] *See* 84 Fed. Reg. 27846, 27867 (June 14, 2019).
[71] 80 Fed. Reg. 54172, 54186 (Sept. 8, 2015).

Additionally, it is important to consider the context of the buildings and facilities at issue under Section 1557. While we affirm that architectural access is essential in all contexts, we note that it is particularly crucial for people with disabilities to have equal access to health programs and activities. People with disabilities already face significant barriers in accessing needed health care, and exempting a health insurance enrollment center or plan benefit counselor from having an elevator or a small health care practice from providing TTY, for example, will only serve to widen the disparities in health access.[72] By choosing to operate a business that is critical to an individual's health and life, and then by choosing to accept HHS funds, private health entities have also assumed a duty to ensure that their buildings and facilities are accessible for all. These are also obligations that are inevitably included in the contracts that health entities enter when they agree to function as a plan or provider with Medicaid, Medicare, or through an Exchange. Watering down this responsibility is unacceptable and unlawful. It will function to reward those few construction or alteration projects that did not have the foresight to take account of the needs of health care consumers with disabilities.

As to the two exemptions that HHS specifically requests comment on, CCD strongly opposes them both. The 2010 Standards provide, in relevant part, that:

> [i]n private buildings or facilities that are less than three stories or that have less than 3000 square feet (279 m^2) per story, an accessible route shall not be required to connect stories provided that the building or facility is not . . . the professional office of a health care provider . . . or another type of facility as determined by the Attorney General.[73]

This private elevator exemption dates back to the 1991 ADA Standards for Accessible Design, a time period in which the concept of widespread architectural accessibility was still relatively recent and wherein the construction or addition of accessible elevators was still considered extremely burdensome and costly. Today, private entities have had over 50 years to adjust their architectural designs and consider the needs of people with disabilities.[74] No longer is requiring a multi-story building or facility to have an elevator the foreign concept or perceived burden it once was. Instead, it is required by the law. Rolling back the standards for having an elevator in private health buildings will only serve to erect a new, additional barrier for individuals with disabilities to access needed health programs.

---

[72] *See, e.g.*, Yee, et al., *supra* note 38; Kaye, *supra* note 41.
[73] Section 206.2.3.
[74] The Architectural Barriers Act, the first federal law requiring that facilities designed, constructed, altered, or leased with certain federal funds be accessible for people with disabilities, was signed into law in 1968. *See* 42 U.S.C. §§ 4151–57.

CCD also opposes lowering the private entity TTY standard. Section 217.4.3 of the 2010 Standards provides, in relevant part, that "[w]here at least one public pay telephone is provided in a *public building*, at least one public TTY shall be provided in the building" and "[w]here four or more public pay telephones are provided in a *private building*, at least one public TTY shall be provided in the building."[75] The lower 4:1 TTY standard for private entities, which originated 15 years ago,[76] is now outdated given the current widespread availability and affordability of the technology. It takes little effort or cost for covered entities to provide 1:1 TTY, yet the benefits offered to people who are Deaf or have hearing impairments are significant.

Although TTY is not as commonly used as it once was, there are certain populations that still rely on TTY, including people who are DeafBlind, people living in rural areas, and senior citizens. For these individuals, TTY critically enables communication with their health care providers, their insurance companies, and other similar entities. Accordingly, HHS should not lower the 1:1 TTY standard for private health care entities.

We also encourage HHS to explicitly incorporate standards that require covered entities to accommodate newer communication technologies that are being used by people with disabilities. Since the establishment of the TTY standards, new innovations such as real-time text ("RTT") have emerged. We urge HHS to codify language that both retains the existing TTY ratios and also adopts similar RTT ratios, in order to be inclusive of modern technologies. Like TTY, all health care entities should be held to more stringent public entity RTT ratios.[77] This addition will help ensure that the Section 1557 regulations stay up-to-date with technological developments.

RECOMMENDATIONS:

- **HHS should continue to apply the 2010 ADA Standards' definition of "public building or facility" to all entities covered under Section 1557.**
- **HHS should not incorporate the private multistory building elevator exemption into Section 1557 regulations.**

[75] Section 217.4.3.1; Section 217.4.3.2.
[76] The 4:1 private TTY standard was first adopted in the 2004 ADA Accessibility Guidelines ("ADAAG").
[77] The Federal Communications Commission has adopted rules to facilitate a transition from TTY technology to RTT technology, which HHS could look to for guidance. *See* 47 C.F.R. Part 67.

- **HHS should not lower the 1:1 TTY ratio for private entities under Section 1557. It should retain the existing TTY ratios and also adopt stringent RTT ratios.**

C. Medical Diagnostic Equipment Standards

CCD further recommends that HHS reference and incorporate the U.S. Access Board's Standards for Accessible Medical Diagnostic Equipment, published at 36 C.F.R. Part 1195, into 45 C.F.R. § 92.203 (as redesignated § 92.103).

In its 2016 Final Rule, HHS considered but ultimately declined to adopt specific language regarding accessibility standards for medical diagnostic equipment into Section 1557.[78] It explained that "the United States Access Board is currently developing standards for accessible medical diagnostic equipment and, therefore, we are deferring proposing specific accessibility standards for medical equipment."[79] HHS OCR has further made clear that "[o]nce the United States Access Board standards are promulgated, OCR intends to issue regulations or policies that require covered entities to conform to those standards."[80]

On January 9, 2017, the U.S. Access Board finalized and published its comprehensive Standards for Accessible Medical Diagnostic Equipment.[81] Thus, it is now appropriate and necessary to incorporate these standards into the Section 1557 regulations. Specifically, we recommend that 45 C.F.R. § 92.203 (redesignated § 92.103) incorporate a subsection as follows:

(a) If a facility or part of a facility in which health programs or activities are conducted purchases or replaces medical diagnostic equipment on or after [30 DAYS FROM DATE OF PUBLICATION OF FINAL RULE], then such newly-acquired equipment shall comply with the 2017 Standards for Accessible Medical Diagnostic Equipment at 36 CFR part 1195.

(b) Each facility or part of a facility in which health programs or activities are conducted shall fully comply with the 2017 Standards for Accessible Medical Diagnostic Equipment at 36 CFR part 1195 by or before [24 MONTHS FROM DATE OF PUBLICATION OF FINAL RULE].

[78] *See* 81 Fed. Reg. at 31422.
[79] *Id.*
[80] 80 Fed. Reg. at 54187 (Sept. 8, 2015).
[81] ATBCB, *Standards for Accessible Medical Diagnostic Equipment: Final Rule*, 82 Fed. Reg. 2810 (Jan. 9, 2017) (codified at 36 C.F.R. Part 1195).

While we recognize that HHS must still develop scoping requirements for these standards and that this process will take time, we emphasize that this development process should begin now and, while the Section 1557 regulations are being otherwise amended, the U.S. Access Board standards should be codified. CCD is deeply aware of the degree to which the common lack of accessible medical equipment presents grave barriers to effective health care for people with mobility, strength, and other disabilities.[82] Now that we have comprehensive standards to combat these widespread access barriers, HHS should take steps to require health care facilities to follow them.

RECOMMENDATION: At 45 C.F.R. § 92.203 (redesignated § 92.103), HHS should incorporate the follow subsection:

(c) If a facility or part of a facility in which health programs or activities are conducted purchases or replaces medical diagnostic equipment on or after [30 DAYS FROM DATE OF PUBLICATION OF FINAL RULE], then such newly acquired equipment shall comply with the 2017 Standards for Accessible Medical Diagnostic Equipment at 36 CFR part 1195.

(d) Each facility or part of a facility in which health programs or activities are conducted shall fully comply with the 2017 Standards for Accessible Medical Diagnostic Equipment at 36 CFR part 1195 by or before [24 MONTHS FROM DATE OF PUBLICATION OF FINAL RULE].

D. "Accessibility of Electronic and Information Technology" (§ 92.204; Proposed § 92.104)

CCD supports HHS' proposal to retain the provisions of 45 C.F.R. § 92.204 (redesignated § 92.104), regarding information and communication technology ("ICT") for individuals with disabilities. Like effective communication, access to information, communication, and electronic technologies is important to guaranteeing people with disabilities equal access to health care services—and this fact is even more true as U.S. society increasingly relies on digital and web-based communications. Health care providers and health insurance plans are rapidly developing interactive websites, moving their medical recordkeeping online, and communicating with patients through

[82] *See, e.g.*, Nancy M. Mudrick, Mary Lou Breslin, et al., *Physical Accessibility in Primary Health Care Settings: Results from California On—Site Reviews*, 5 DISABILITY & HEALTH J. 159–67 (2012); Tara Lagu, et al., *Access to Subspecialty Care for Patients with Mobility Disabilities: A Survey*, 158 ANN. INTERN. MED., no. 6, 441–46 (2013).

electronic means. We commend HHS' efforts to ensure that people with disabilities are not left behind as technologies evolve.

We are, however, concerned with HHS' proposed change to the definition of "information and communication technology" in proposed § 92.104(c). While we generally object to the elimination of the definitions section at 45 C.F.R. § 92.4, we do appreciate that HHS has incorporated the definition of ICT from the U.S. Access Board regulations implementing Section 508 of the Rehabilitation Act. We note, however, that a critical phrase was removed from the U.S. Access Board's definition. The second sentence of the U.S. Access Board's definition reads: "Examples of ICT include, *but are not limited to*: . . ." (emphasis added).[83] HHS has removed the phrase "but are not limited to" in its NPRM. We strongly encourage HHS to keep this phrase. Information and communication technologies are constantly evolving; it is difficult to predict what technologies will be in place in 5, let alone 10 or 20, years. In order to maintain flexibility and ensure that the regulations keep pace with emerging technologies, HHS should make it absolutely clear that its list of examples of ICT is not exclusive.

Finally, HHS requests comment on whether it should cross-reference Section 508 and its applicable implementing regulations in proposed § 92.104.[84] CCD supports this proposal. Cross-referencing Section 508 and its regulations will help ensure that the Section 1557 regulations stay up-to-date as the Section 508 regulations are amended, and it will ensure consistency across the civil rights laws.

RECOMMENDATIONS:

- **HHS should amend the second sentence of proposed § 92.104(c) to read "Examples of ICT include, <u>but are not limited to</u>: . . .".**

- **HHS should cross-reference Section 508 and its applicable implementing regulations in proposed § 92.104.**

E. "Requirement to Make Reasonable Modifications" (§ 92.205; Proposed § 92.105)

The proposed text of 45 C.F.R. § 92.105 mirrors the current text of 45 C.F.R. § 92.205 and retains the requirement to make reasonable modifications to policies, practices, or procedures. We support this language. This language of "reasonable modification" conforms to other non-discrimination regulations that apply to state and local

[83] 36 C.F.R. app. A § 1194 (2011).
[84] *See* 84 Fed. Reg. 27846, 27867–68 (June 14, 2019).

government, and therefore is consistent with other regulatory schemes applicable to entities subject to 1557.[85] The 2016 Final Rule specifically applies the definition of "reasonable modification" from Title II of the ADA (state and local governments), which we believe continues to be the appropriate standard for recipients of federal financial assistance, programs established under Title I of the ACA, and programs administered by HHS. The concept of "reasonable modification" is not burdensome. The concept has long applied to a broad swath of entities, whether public or private, and therefore it is clear and familiar to most entities covered by Section 1557.[86] There is no reason to make any changes to this language, nor to import unrelated concepts from other regulatory schemes.

HHS has requested comment on whether the following language should be substituted for the proposed 45 C.F.R. § 92.105: covered entities shall make "reasonable accommodation to known physical or mental limits of an otherwise qualified" individual with a disability. HHS also asks whether an exemption for "undue hardship" should be imported from 45 C.F.R. § 84.12 and 28 C.F.R. § 92.205 into proposed 45 C.F.R. § 92.105. The substitute language is from regulations related to employment, and is unnecessary, ill-fitting, and inappropriate for a health care context. The answer to both questions is no. HHS should not make any changes to the language at current § 92.205.

As a preliminary matter, in asking about the imported language, HHS states that the language is taken from HHS Section 504 regulations and the "Department of Justice's Section 504 coordinating regulation."[87] However, the citations to the DOJ Section 504 coordinating regulations are to a non-existent portion of the Code of Federal Regulations.[88] These incorrect citations makes it impossible for the public to know with certainty what HHS is proposing, nor does it allow the public to analyze the context of

[85] *See* 45 C.F.R. § 92.205 (2016).
[86] *See, e.g.,* 28 C.F.R. § 35.130(b)(7) (2010) ("A public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.")(Title II of the ADA). Title III also incorporates a requirement that covered entities make "reasonable modifications in policies, practices, or procedures, when the modifications are necessary to afford goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities, unless the public accommodation can demonstrate that making the modifications would fundamentally alter the nature of the goods, services, facilities, privileges, advantages, or accommodations." 28 C.F.R. § 36.302(a) (2010).
[87] 84 Fed. Reg. 27846, 27868 (June 14, 2019).
[88] *Id.* (citing to 28 C.F.R. § 92.205 two separate times: 28 C.F.R. Part 92 contains regulations regarding the "Office of Community Oriented Policing Services (COPS)," and does not contain a section 92.205).

the proposed imported language, or any case law interpreting such language.[89] Public comment requires transparency, and the source of any imported language is an integral part of transparency.

Furthermore, new exemptions are unnecessary and contrary to Section 1557. The concept of a "reasonable modification" is not boundless—it is already well-defined by regulation and decades of case law. In fact, the definition of "reasonable modification" is so clear that HHS declined to provide additional explanation of the term in the 2016 Final Rules.[90] The 2016 final regulations track Title II of the ADA, requiring covered entities to make a reasonable modification "unless the covered entity can demonstrate that making the modifications would fundamentally alter the nature of the health program or activity."[91] Continuing to apply the "reasonable modification" analysis to Section 1557 promotes consistency with pre-existing civil rights statutes, one of HHS' stated goals of their NPRMs.[92] Neither Section 504 nor Title II of the ADA would permit an exemption for "undue hardship" in this context, and it is inappropriate to import such an exemption into Section 1557 where none exists in the statute itself.

The suggested imported language of "reasonable accommodation," "known physical or mental limitation," and "undue hardship" stems directly from employment-related regulations. Such concepts are ill-fitting in the health care context and cannot be applied under Section 1557. For example, the definition of "undue hardship" makes little sense when divorced from the employment context, as it requires consideration of factors often irrelevant to the health care context, such as "(1) The overall size of the recipient's program or activity with respect to number of employees, number and type of facilities, and size of budget; (2) The type of the recipient's operation, including the composition and structure of the recipient's workforce; and (3) The nature and cost of the accommodation needed."[93] These factors make sense in an employment context; they do not when applied to health care. For example, the composition and structure of a

[89] It appears that HHS seeks to import DOJ's rules for the implementation of Executive Order 12250. *See* 28 C.F.R. § 41.53 (2002). It is also possible that HHS intends to refer to DOJ's rules for reasonable accommodation in employment in federally assisted programs pursuant to Section 504. *See* 28 C.F.R. § 42.511 (2000). Either way, it is incumbent on HHS to accurately explain the source of any regulations it seeks to substitute.
[90] *See* 81 Fed. Reg. 31375, 31382 (May 18, 2016) ("OCR believes that defining the terms ''reasonable modification'' and ''accessibility'' in this rule is unnecessary, given the meaning that these terms have acquired in the long history of enforcement of Section 504 and the ADA in the courts and administratively. We intend to interpret both terms consistent with the way that we have interpreted these terms in our enforcement of Section 504 and the ADA and so decline to add these definitions to the final rule").
[91] 45 C.F.R. § 92.205 (2016).
[92] 84 Fed. Reg. 27848 (June 14, 2019).
[93] 45 C.F.R. § 84.12 (2010).

workforce and the number of employees is relevant to common employment-related accommodations, such as changes in job duties or schedules. These factors are much less likely to have bearing on common health care modifications, which may more commonly include requests for alternative evacuation plans for individuals who cannot use stairs, additional training for health care staff on how to provide services to certain individuals, ensuring lab referrals are made to accessible entities when necessary, or altering a policy to allow an individual to remain in a wheelchair and avoid unnecessary transferring while receiving some treatments such as dental care. Because the factors used to analyze “undue hardship” are more appropriate for the employment context, we believe that the appropriate approach is to retain the “reasonable modification” language, which is taken from Title II of the ADA, already applies to many entities subject to Section 1557, and has a clear definition that is flexible enough to provide guidance to health care entities.

We specifically object to the importation of the concept of “known physical or mental limitation” because it could introduce confusion, suggest that covered entities' obligations are limited, and unduly focuses on measures entities must take in response to requests for modifications. Disability discrimination encompasses not just inappropriate responses to requests for modifications, but also a failure of covered entities to take affirmative steps to prevent discrimination. Taken in conjunction with the proposed deletion of § 92.101 which defines discriminatory actions prohibited (discussed *supra,* Section II(D)), importing the language regarding "known physical or mental limitation" could be read to limit covered entities' obligations. Nothing in Section 1557 permits such limitations, and such a reading would be contrary to the language of Section 1557 and the larger Act within which it sits. Nor has HHS provided an explanation of how this concept, which heretofore has been largely limited to the employment context, would be applied in the health care context. Such an application would undermine HHS’ stated purpose of the proposed rule, which is to promote consistency in the application of rules and to adhere to the enforcement mechanisms available in the underlying statutes.[94]

Furthermore, while we disagree with HHS’ statement that Congress only intended to permit disparate impact claims if such claims were permissible prior to 1557, HHS admits that many courts have permitted disparate impact claims under Section 504.[95] Importing language regarding “known” limitations could be interpreted as limiting plaintiffs’ ability to bring systemic disparate impact claims, or other substantive claims. If HHS intends to create such a limitations, it must be explicit about its intent, and do so

[94] 84 Fed. Reg. 27848, 27849-51 (June 14, 2019).
[95] *See, e.g., McWright v. Alexander,* 982 F.2d 222, 229 (7th Cir. 1992); *Smith v. Barton*, 914 F.2d 1330, 1340 (9th Cir. 1990).

via a transparent rulemaking process. If HHS does not intend to create such a limitation, we request that HHS retain the language in proposed 45 C.F.R. § 92.105.

For the reasons stated above, we urge HHS to retain the language proposed in § 92.105 as drafted, and not to import any new exemptions or language regarding "reasonable accommodations to known physical and mental impairments."

RECOMMEDNATIONS:

- **HHS should not import an "undue hardship" exemption into the regulations related to reasonable modification.**
- **HHS should retain the current language of "reasonable modification."**

F. Comments on Proposed §§ 92.102 through 92.105

HHS has asked broadly whether it has struck the "appropriate balance" in proposed §§ 92.102 through 92.105 with respect to Section 504 rights and obligations imposed on the "regulated community." We agree generally that to the extent that HHS has retained protections from the 2016 Final Regulations, such protections are appropriate. More broadly, however, the question should not be "whether the benefits of these provisions exceeds the burdens imposed by them." Such a balancing exercise is not called for by the statute, and inserts an inappropriate regulatory finesse on a remedial scheme created by Congress and intended to be interpreted broadly to correct decades of harm.[96] The task of the agency is to interpret and implement the statute. The proposed balancing of interests may be an appropriate role for Congress, but not for the administrative branch. Although we disagree with the premise of the question, we do note that the harm that people with disabilities would suffer if Section 1557 and the current regulatory scheme were not upheld is immense.[97]

HHS also asks generally whether regulations for Section 1557 are consistent with the regulatory scheme for entities that are not covered by Section 1557 regulations, such as human services grantees, or whether underlying regulations for other civil rights statutes need to be modified. In general, we have commented on contexts where it is inappropriate to import regulations created for the employment into Section 1557's regulatory scheme. While there are clearly other areas of nondiscrimination law where

[96] *See, e.g.* 42 U.S.C. § 12101 (1990) (ADA findings and purposes). The ADA built upon Section 504, and Section 1557 follows in their footsteps. *See also Kang v. U. Lim Am., Inc.*, 296 F.3d 810, 816 (9th Cir. 2002); citing H.R. Rep. No. 102–40(I), at 88, U.S. Code Cong. & Admin. News at 626 ("remedial statutes, such as civil rights law[s], are to be broadly construed").
[97] *Supra*, notes 38-42 and accompanying text.

importing or exporting other regulatory regimes would be inappropriate, HHS has not provided sufficient clarity in both the questions and the context to allow us to provide additional meaningful comment outside of the comments raised above.

To propose changes in existing regulations, HHS must provide its own justification for the changes. Given that the public must be provided an opportunity to comment on HHS' alleged explanations and rationale for these proposed changes, HHS' attempt to solicit feedback on unspecified underlying regulations that it may then use to promulgate unanticipated changes in a final rule violates requirements of public notice and comment as required by the Administrative Procedures Act. These issues would be more appropriate to inform agency decisions prior to issuing an NPRM, such as through a Request for Information, than in response to an NPRM. We thus decline to provide feedback additional feedback on the question of whether Section 1557 is generally aligned with underlying but unspecified regulations, but have provided our explanations, justifications and evidence supporting our comments in the sections above.

V. Conclusion

People with disabilities, like all people, have intersectional identities, and the anti-discrimination mandate in Section 1557 is designed to prohibit discrimination based on a single identity as well as the intersection of two or more identities such as race and disability, age and disability, or sex and disability. We therefore strongly oppose the NPRM provisions which seek to eliminate and limit protections for limited English proficient individuals, LGBTQ+ persons, women *and* persons with disabilities and chronic conditions. Section 1557 addresses not only protections for each protected class covered, but the intersection of those protections. As such, an attack on the civil rights of one group in the NPRM is an attack on the civil rights of all. We stand in solidarity with other marginalized groups in objecting to this NPRM.

We strongly recommend that HHS not finalize any part of the proposed changes to the Section 1557 regulations as well as the other conforming provisions. HHS should instead leave the 2016 final Section 1557 regulations in place in their entirety.

Thank you for the opportunity to provide comments on the NPRM. We urge HHS not to finalize these changes. If you have questions about our comments, please contact Jennifer Lav at lav@healthlaw.org.

Sincerely,

Allies for Independence

ALS Association
American Academy of Physical Medicine & Rehabilitation
American Association on Intellectual and Developmental Disabilities (AAIDD)
American Association on Health & Disability
American Association of People with Disabilities (AAPD)
American Council of the Blind
American Dance Therapy Association
American Foundation for the Blind
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Occupational Therapy Association (AOTA)
American Physical Therapy Association
American Therapeutic Recreation Association
Amputee Coalition
Autism Society of America
American Speech-Language-Hearing Association
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Center for Medicare Advocacy
Center for Public Representation
Children and Adults with Attention-Deficit/Hyperactivity Disorder
Christopher & Dana Reeve Foundation
Disability Rights Education & Defense Fund
Easterseals
Epilepsy Foundation
Family Voices
Institute for Educational Leadership (IEL)
Justice in Aging
Lutheran Services in America-Disability Network
National Academy of Elder Law Attorneys
National Association for the Advancement of Orthotics and Prosthetics
National Association of Councils on Developmental Disabilities
National Association of State Head Injury Administrators
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Council on Independent Living
National Disability Institute
National Disability Rights Network
National Down Syndrome Congress
National Health Law Program

National Multiple Sclerosis Society
Paralyzed Veterans of America
Partnership for Inclusive Disaster Strategies
The Arc of the United States

DISABILITY LAW CENTER
Your rights matter.

Public Comment /
Proposed ACA Section 1557 Regulation Revision
August 13, 2019
Andrew Riggle / Public Policy Advocate
(801) 363-1347 / (800) 662-9080
ariggle@disabilitylawcenter.org

Roger Severino
Director, Office for Civil Rights
U.S. Department of Health and Human Services
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

RE: HHS Docket No. HHS-OCR-2019-000, RIN 0945-AA11

Dear Mr. Severino:

The Disability Law Center (DLC) is the federally-mandated protection and advocacy agency for people with disabilities in Utah. We envision a society where persons with disabilities are full and equal citizens under the law, are free from discrimination, and have access to the same opportunities afforded others. Our mission is to enforce and strengthen laws that protect the opportunities, choices and legal rights of the 300,000 Utahns with disabilities. The organization's services are available statewide and free of charge, regardless of income, legal status, language, or place of residence.

The DLC appreciate this opportunity to share our views on these proposed policy changes in interpreting and enforcing the nondiscrimination provision of the Affordable Care Act (ACA). We write to express opposition to the U.S. Department of Health and Human Services (HHS) proposed rule on Section 1557. The proposed rule would cause major harm to people with disabilities and their families and communities; it's unfair, discriminatory and bad policy for this country. We recommend HHS not finalize this regulation in whole or in part.

Section 1557 and its implementing rules are critical because people with disabilities are routinely discriminated against in the provision of health care. For example, patients with mobility challenges continue to have difficulty accessing primary care because physicians offices are often inaccessible or do not have accessible equipment. Persons with sensory impairments also experience challenges understanding or complying with care instructions because interpreters are more often than not unavailable or materials are not offered in alternative formats. Additionally, parity with physical health - if it exists at all - is frequently inadequate for individuals with psychiatric needs, who often require intensive and/or long-term supports. Finally, many of those with cognitive disabilities or who are aging continue to be unnecessarily segregated in nursing homes, institutions, or other facilities. HHS underwent an extensive process to develop regulations for Section 1557, including a Request for Information, proposed rule, and final rule. HHS considered more than 24,875 public comments submitted for the 2016 rule. There is no reason to reopen this rule and ignore the reasoned process HHS has already undertaken.

The DLC requests that HHS retain the current definition of a "covered entity." The proposed rule seeks to radically narrow the scope and applicability of Section 1557, contrary to the plain meaning of the statute. Congress made clear in Section 1557 that if one part of an entity receives federal financial assistance, the entire entity should be covered. It also clearly intended Section 1557 to address discrimination in health insurance. Until recently, unless we intervened, both

Medicaid and private plans routinely denied coverage for medically necessary power wheelchairs and/or communication devices.

The DLC disagrees with HHS' proposal to delete the current requirement that covered entities provide notice, with every significant communication to individuals, that they do not discriminate based on disability or other prohibited grounds; that they provide auxiliary aids and services for people with disabilities, including qualified interpreters and information in alternate formats; and how to obtain those auxiliary aids and services. Without the notice, members of the public will have limited means of knowing that auxiliary aids and services are available, how to request them, what to do if they face discrimination, and their right to file a complaint. As HHS itself notes in the proposed rule, "repealing the notice of nondiscrimination requirement may result in additional societal costs, such as decreased utilization of auxiliary aids and services by individuals with disabilities due to their reduced awareness of such services." We agree, and therefore object to removing this requirement.

HHS should retain strong, clear language prohibiting insurance companies from discriminating on the basis of race, color, national origin, sex, age, or disability in a number of areas, including marketing plans, designing benefits, coverage claims, or imposing additional costs. These protections are especially important for people with disabilities and those with serious or chronic conditions. Eliminating this regulatory provision could result in health insurers illegally excluding important benefits, designing their prescription drug formularies in a way that limits access to medically necessary care, or cherry-picking healthier enrollees through marketing practices. It may make it harder for people who experience discrimination to enforce their rights through administrative and judicial complaints.

We urge HHS to retain the language in the 2016 Final Rule regarding effective communication for individuals with disabilities. In the proposed rule, HHS changes the definition of auxiliary aids and services, and does so without explanation. HHS claims to import the definition of auxiliary aids and services from the regulations for Title II of the Americans with Disabilities Act, but deletes "[a]cquisition or modification of equipment and devices; and [o]ther similar services and actions" from the list of examples of aids and services. This could create confusion, as it takes what is now a clearly illustrative list and implies that it is exhaustive. HHS should retain the definition of "auxiliary aids and services" from the 2016 final rule. Furthermore, we oppose any proposal to exempt entities with 15 or fewer employees from the requirement to provide effective communication. In some areas of the country, this could effectively bar access to many providers, including specialists who are essential to providing high quality health care to individuals with chronic health conditions. For instance, while 75% of Utahns live along the urban Wasatch Front, a quarter live in the remaining 90% of the state, which is primarily made up of small, rural communities with anywhere from a couple hundred to a few thousand residents.[i] According to a 2015 survey, 8% of Utah's physicians and only 5.5% of specialists work in a rural county.[ii]

The DLC opposes HHS' proposal to delete regulations that prohibit discrimination on the basis of association with a protected class. This will create uncertainty and confusion regarding the responsibilities of providers and the rights of persons who experience discrimination, and inconsistencies with other regulatory requirements that entities are subject to, including the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.
The DLC also believes that HHS incorrectly limits the remedies available under Section 1557 in the proposed changes to § 92.301 (newly designated § 92.5). One of the goals of Section 1557 was to build and expand on prior civil rights laws such that individuals seeking to enforce their rights would have access to the full range of available civil rights remedies and not be limited to only the remedies provided to a particular protected group under prior civil rights laws. This is

why Section 1557 expressly provides individuals access to any and all of the "enforcement mechanisms provided for and available under" the cited civil rights statutes, regardless of the type of discrimination. The proposed rule makes it harder and more complicated to address prohibited discrimination. HHS should retain current § 92.301.

HHS seeks comments on a number of other proposed changes which the DLC opposes. The Sec. 1557 final rule was the subject of a lengthy development process that included substantial public input and comment. Revisiting all of the previously settled issues in the final rule, particularly those far beyond the justification offered in the NPRM, creates uncertainly and further weakens finality. HHS should not change the current requirements to provide "reasonable modification," and import exemptions for "undue hardship," The substitute language is from regulations related to employment, and is unnecessary, ill-fitting, and inappropriate for a health care context. Exemptions should not exist regarding elevators in multistory buildings, as this is likely to severely limit access to necessary medical care. Last, we note that people with disabilities, like all people, have intersectional identities, and that the anti-discrimination mandate in 1557 is designed to prohibit discrimination based on a single identity as well as the intersection of two or more identities such as race and disability, age and disability, or sex and disability. The proposed rule seeks to strip protections from persons with limited English proficiency, LGBTQ individuals, and women. We stand in solidarity with other marginalized groups in objecting to this proposed rule.

Thank you for the opportunity to provide comments on the proposed rule. The Disability Law Center urge HHS not to finalize these changes. If you have questions about our comments, please do not hesitate to contact us.

[i] University of Utah, Kem C Gardner policy Institute (January 2018). Factsheet: Utah at a Glance. https://gardner.utah.edu/wp-content/uploads/UtahAtAGlance_20180207.pdf.

[ii] Utah Medical Education Council (2016). Utah's Physician Workforce, 2016: a Study on the Supply and Distribution of Physicians in Utah. https://umec.utah.gov/wp-content/uploads/2016-Physicians-Report-Final.pdf.

Disability Rights Education & Defense Fund DREDF

August 13, 2019

Roger Severino, Director
Office for Civil Rights
Department of Health and Human Services
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

via Online Portal (www.regulations.gov)

RE: HHS-OCR-2019-0007; Nondiscrimination in Health and Health Education Programs or Activities (RIN 0945-AA11)

Dear Director Severino:

The Disability Rights Education and Defense Fund ("DREDF") appreciates the opportunity to provide comment on the proposed rule to revise the regulations implementing Section 1557 of the Patient Protection and Affordable Care Act ("ACA"). DREDF is a national cross-disability law and policy center that protects and advances the civil and human rights of people with disabilities through legal advocacy, training, education, and development of legislation and public policy. We are committed to increasing accessible and equally effective healthcare for people with disabilities and eliminating persistent health disparities that affect the length and quality of their lives.

DREDF is gravely concerned with HHS' proposed amendments to the Section 1557 regulations. While we appreciate that HHS seeks to reduce costs and improve health plan sustainability, these goals cannot be sought at the expense of the civil rights of health care consumers—and particularly those individuals and families who already face pervasive physical, programmatic, and attitudinal barriers in the health care context. The proposed changes to the Section 1557 regulations would significantly weaken the civil rights of already disadvantaged groups, and it will have a disproportionately harmful effect on the provision of health care for, and the health outcomes experienced by, people with disabilities. Such harms are not what Congress intended in enacting the ACA and, as a federal agency charged with promulgating regulations that are consistent with the text and purposes of the enabling statute, HHS would exceed its legally permitted scope of authority by finalizing them.

In enacting the ACA in 2010, Congress sought to ensure that all Americans, including Americans with disabilities, have equal and comprehensive access to health insurance coverage. Prior to the ACA, people with disabilities were commonly denied or terminated from health coverage,

faced annual and lifetime benefit limits, and could not find affordable coverage.[1] Even if a disabled individual could find health insurance, it would often exclude coverage of pre-existing conditions, fail to offer essential benefits, or otherwise limit benefits based on health status or disability. With the ACA, Congress explicitly outlawed these longstanding discriminatory policies, and Section 1557 was the key to enforcing these reforms. The ACA expanded access to basic health insurance coverage; it created protections in enrollment, cost-sharing, and benefit design; and it improved the scope and quality of essential health care benefits. *See* 42 U.S.C. §§ 300gg-3(b)(1), 18022, 18031(c)(1)(A). Section 1557 serves as the enforcement mechanism of these equitable reforms—placing an outer limit on the permissible practices of health plans and health providers. *See id.* § 18116(a). While the ACA did not require a health plan to offer every possible service or a health provider to offer every possible accommodation, it did require them to offer certain minimum features to meet the basic needs of Americans, without excluding or limiting them from care because of their race, age, sex, or disability. In order to protect the basic civil rights of people with disabilities in health care, it is essential that Section 1557's regulations remain fair and comprehensive.

In these comments, DREDF provides section-by-section analysis of how the proposed changes to the Section 1557 regulations would harm health care consumers and undermine the ACA's clear objectives. While the primary focus of these comments is on the impact that the proposed rules would have on people with disabilities, in Sections IV and V, we also briefly highlight prospective impacts on other historically marginalized groups, whose identities often intersect with disability.

[1] *See generally, e.g.*, Valarie K. Blake, *An Opening for Civil Rights in Health Insurance After the Affordable Care Act*, 36 B.C. J. L. & SOC. JUST. 235 (2016) (describing pre-ACA health insurance discrimination and how the ACA addressed those issues); Sara Rosenbaum et al., *Crossing the Rubicon: The Impact of the Affordable Care Act on the Content of Insurance Coverage for Persons with Disabilities*, 25 NOTRE DAME J. L. ETHICS & PUB. POL'Y 235 (2014) (describing the ACA's nondiscrimination provisions and focusing on the function of its essential health benefit requirements).

I. SCOPE OF APPLICATION

A. Covered Entities (45 C.F.R. §§ 92.1, 92.2, 92.4, Proposed § 92.3)

DREDF strongly opposes HHS' proposal to limit the scope of covered entities under Section 1557. Regulations currently define "health program or activity" to properly cover "all [] operations" of "entit[ies] principally engaged in providing or administering health services or health insurance coverage or other health coverage." 45 C.F.R. § 92.4. Furthermore, existing rules correctly apply Section 1557 to any program or activity administered HHS, not just programs established under Title I of the ACA. *Id.* § 92.2. The Proposed Rule attempts to severely limit the scope of covered health programs and activities under these provisions, in a proposal that directly contradicts the statutory text of Section 1557 and the purposes of the ACA. HHS should refrain from narrowing the scope of the current regulations.

i. Health Insurers Are "Health Programs or Activities," For Which All Operations Are Subject to Section 1557

DREDF strongly opposes the proposal at § 92.3 to restrict the scope of Section 1557's application to health care insurers. The Proposed Rule incorrectly interprets "health programs and activities" to exclude health insurers, and it erroneously incorporates the Civil Rights Restoration Act ("CRRA") into Section 1557. These proposed revisions are contrary to Section 1557's clear statutory language and should not be codified.

Section 1557 prohibits disability-based discrimination in "any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under this title [of the ACA]." 42 U.S.C. § 18116(a). HHS' 2016 interpretation of "health program or activity" to include health insurers (and, in accordance with the statutory language, to cover all of these insurers' activities if any part of their operations receives federal financial assistance) was not only appropriate, it was required by the law. The statutory language that Congress used in Section 1557 is extremely broad, covering "*any* health program or activity." Health insurers clearly have a significant role in the provision of health care, including controlling access to health care services through benefit design, utilization management, and other means. Moreover, the *primary purpose* of the ACA was to expand the availability and scope of health insurance and assist individuals in securing and enrolling in health insurance coverage. Further, the debate about the non-discrimination provisions during the passage of the ACA was specifically about discrimination in insurance. If Congress meant to exclude health insurance from the term "health program or activity"—particularly in a law that is *about* health insurance—certainly it would have made this point clear. Thus, the 2016 Final Rule's definition of health program or activity ("the provision or administration of health-related services, health-related insurance coverage, or other health-related coverage, and the provision of assistance to

individuals in obtaining health-related services or health-related coverage"[2]) reflects the clear language and intent of the law.[3]

In the proposal at hand, HHS re-interprets "health program or activity," concluding that an entity "principally or otherwise engaged in the business of providing health insurance shall not, by virtue of such provision, be considered to be principally engaged in the business of providing health care." 84 Fed. Reg. at 27850, 27891. It further states that federal financial assistance to *any part* of such an entity is not sufficient to trigger coverage of the entity under Section 1557, a conclusion entirely inconsistent with its statutory language.

The only justification that HHS offers for reading health insurance out of "health care" is a reference to another federal statute (5 U.S.C. § 5371) with an entirely different purpose, which defines "health care" for purposes of that law as "direct patient-care services or services incident to direct patient care-services." *See* 84 Fed. Reg. at 27850, 27863. That law, however, concerns pay rates and personnel practices for federal employees, and it uses the term "health care" simply to describe a category of federal employees who work in that sector. It would make little sense for that law to include individuals engaged in providing health insurance, as the federal government does not employ a large set of individuals to provide health insurance. Using an unrelated law with a different purpose to define health insurance largely out of the non-discrimination provisions of a law that is *about health insurance* is without foundation and inconsistent with the statute that HHS is interpreting.

Furthermore, the Proposed Rule incorrectly attempts to incorporate the CRRA directly into Section 1557. *See* 84 Fed. Reg. at 27846, 27850. The CRRA is a federal statute that clarifies the scope of application of Section 504, Title VI, Title IX, and the ADEA. Pub. L. 100-259, 102 Stat. 28 (Mar. 22, 1988). The CRRA predates the ACA and nothing in its text applies its provisions to future statutes. *See id.* Likewise, in enacting the ACA in 2010, Congress did not incorporate the CRRA into Section 1557, even though it had the opportunity to do so. *See* 42 U.S.C. § 18116(a)

Despite these clear statutory findings, HHS' proposal attempts to incorporate the CRRA's definition of "program or activity" receiving federal financial assistance ("FFA") into Section 1557,

[2] 45 C.F.R. § 92.4. The Final Rule further specified that, for an entity "principally engaged in providing or administering health services or health insurance coverage or other health coverage" (including all health insurers), all of its operations are subject to Section 1557. *Id*.

[3] HHS acknowledged in the 2016 Final Rule that there are concerns about excluding Medicare Part B from the definition of federal financial assistance. HHS Nondiscrimination in Health Programs and Activities; Final Rule, 81 Fed. Reg. 31376, 31384 (May 18, 2016) (hereinafter "2016 Final Rule"). However, because HHS determined that the Section 1557 rule was not the appropriate place to change its position on the issue, we do not raise those concerns here.

in an attempt to limit the scope of covered operations of health insurers. The CRRA clarified that private entities are covered by relevant laws (Section 504, Title VI, and Title IX) if their programs or activities receive FFA "as a whole" or if the entity is "principally engaged in the business of providing . . . health care . . . ."[4] HHS—now having arbitrarily defined health insurance out of "the business of providing health care"—attempts to apply a pre-ACA law, whose application to the ACA is unfounded and unnecessary, to assert that health insurers are only covered by Section 1557 to the extent that a particular operation receives FFA.

This proposal is illogical and plainly inconsistent with the statutory language of Section 1557. Congress has already answered the question of whether coverage under Section 1557 requires FFA for *part* of a program or activity or for its operations as a *whole*: it expressly stated in the statute that any health program or activity is covered if "any part" of it receives FFA. 42 U.S.C. § 18116(a). The Proposed Rule ignores this clear statutory language. There is simply no logical way to interpret Section 1557's language to be consistent with HHS' new interpretation.

Furthermore, to the extent that HHS relies on Section 1557's references to the "grounds" and "enforcement mechanisms" of Section 504, Title VI, Title IX, and the ADEA in order to incorporate the CRRA, note that the U.S. Supreme Court has already held that a statute's incorporation of another statute's enforcement mechanisms does not necessarily incorporate its substantive law. *See CONRAIL v. Darrone*, 465 U.S. 624 (1984) (holding that Section 504's incorporation of the "remedies, procedures, and rights" set forth in Title VI did not mean that Section 504 incorporated Title VI's substantive limitations on actionable discrimination). The incorporation of the CRRA into Section 1557 will not withstand judicial scrutiny.

ii. All Health Programs Administered by HHS (Not Just Those Created Under ACA Title I) Are Covered Entities Under Section 1557

DREDF also objects to the proposed rules that seek to narrow the scope of Section 1557 as it applies to HHS activities and programs receiving FFA from HHS. Section 1557, by its statutory terms, applies to all health programs administered or financially supported by HHS. The Proposed Rule, as currently formulated, unlawfully narrows the departmental entities it covers. *See* Proposed 45 C.F.R. §§ 92.2, 92.3. It seeks to exclude a wide range of important HHS activities, including, e.g., programs administered by the Health Resources and Services Administration ("HRSA"), which support the health care workforce and improve health care for people who are geographically isolated or medically vulnerable. This proposal stands contrary to the statutory text, design, and intent of Section 1557 and the ACA.

[4] HHS Nondiscrimination in Health and Health Education Programs or Activities; Proposed Rule, 84 Fed. Reg. 27846, 27850, 27862 (June 14, 2019) (hereinafter "2019 Proposed Rule").

The plain language of Section 1557, as well as the 2016 Final Rule, establishes that any health "program or activity" administered by an Executive agency is subject to the law's provisions. 42 U.S.C. § 18116(a); 42 C.F.R. §§ 92.1, 92.2, 92.4. HHS' new interpretation of Section 1557 impermissibly changes the word "or" to "and," in an attempt to narrow the rule's application to only health programs or activities administered by an Executive agency "and" created under Title I of the ACA. *See* 84 Fed. Reg. at 27862. This reading is inconsistent with the statute, which uses the word "or," thereby plainly prohibiting discrimination by both programs or activities "administered by an Executive Agency" *as well as* those entities "established under" ACA Title I. If Congress had intended to limit Section 1557 to only those entities created under Title I, it would not have included the additional clause pertaining to Executive agencies.

Moreover, this proposal would produce illogical results. It would create a situation whereby recipients of FFA would be subject to Section 1557's nondiscrimination requirements, but agencies administering or funding such programs would be exempt. For example, state Medicaid programs would be subject to Section 1557 as recipients of FFA, but the Centers for Medicare and Medicaid Services ("CMS"), which oversees these programs, would be exempt. Such an interpretation is not only inconsistent with the plain meaning of Section 1557, but also inconsistent with Section 504 and therefore likely to cause significant confusion. HHS and all of its components, including CMS, HRSA, the Centers for Disease Control and Prevention ("CDC"), and the Substance Abuse and Mental Health Services Administration ("SAMHSA"), are subject to Section 504, *see* 29 U.S.C. § 794; 45 C.F.R. Part 85, as well as Section 1557.

Finally, the narrowing of Section 1557's application will have a disproportionate impact on people with disabilities, contrary to the purposes of the ACA. People with disabilities have been and continue to be systemically disadvantaged by the U.S. health system, which has fragmented funding and delivery systems, an institutional bias in its provision of long-term services and supports (that many people with disabilities rely on to live, work, attend school, and participate in their communities), and a long history of exclusion of people with disabilities from research and clinical trials, to name just a few troubling issues in a history of unequal treatment. This narrow and incorrect interpretation of Section 1557's application to HHS programs will only serve to exacerbate these systemic discriminatory disparities. As HHS itself has stated in the context of the Section 1557 regulations, "a fundamental purpose of the ACA is to ensure that vital health care services are broadly and nondiscriminatorily available to individuals throughout the country."[5] This proposal certainly does not further, and indeed will undermine, this goal.

RECOMMENDATION: HHS should retain the current regulations addressing the applicability of Section 1557 in their entirety, and it should not finalize proposed 45 C.F.R. §§ 92.2, 92.3.

[5] HHS Nondiscrimination in Health Programs and Activities; Proposed Rule, 80 Fed. Reg. 54172, 54172 (Sept. 8, 2015) (hereinafter "2015 Proposed Rule").

II. DISCRIMINATION GENERALLY

A. Discrimination Prohibited (45 C.F.R. § 92.101)

DREDF opposes HHS' proposal to eliminate 45 C.F.R. § 92.101. While HHS claims that it will replace this regulation with "provisions addressing Section 1557's purpose, nondiscrimination requirements, scope of application, enforcement mechanisms, relationship to other laws, and meaningful access for LEP individuals," 84 Fed Reg. at 27856, 27860, the Proposed Rule fails to incorporate important prohibitions on discrimination that are currently contained in § 92.101.

By eliminating § 92.101(b)(2), HHS deletes references to important regulatory definitions of disability discrimination. For example, the current regulation states that "Each recipient and State-based Marketplace[SM] must comply with the regulation implementing Section 504, at §§ 84.4(b), 84.21 through 84.23(b), 84.31, 84.34, 84.37, 84.38, and 84.41 through 84.52(c) and 84.53 through 84.55 of this subchapter." 45 C.F.R. § 92.101(b)(2)(i). It also states that "[t]he Department, including the Federally-facilitated Marketplaces, must comply with the regulation implementing Section 504, at §§ 85.21(b), 85.41 through 85.42, and 85.44 through 85.51 of this subchapter." *Id.* § 92.101(b)(2)(ii). These cross-references clarify that covered entities have an affirmative obligation to ensure that their health care is accessible to individuals with disabilities in a myriad of ways that are not captured in other sections of the Proposed Rule.

For example, §§ 84.4(b) and 85.21(b) prohibit the following forms of disability discrimination: denying individuals with disabilities the opportunity to participate; affording unequal opportunity to participate; providing a less effective aid, benefit or service; providing different or separate aids, benefits, or services; or otherwise limiting a person with a disability in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving an aid, benefit, or service. These regulations also prohibit covered entities from "utiliz[ing] criteria or methods of administration (i) that have the effect of subjecting qualified handicapped persons to discrimination on the basis of handicap, (ii) that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the recipient's program or activity with respect to handicapped persons, or (iii) that perpetuate the discrimination of another recipient if both recipients are subject to common administrative control or are agencies of the same State." 45 C.F.R. §§ 84.4(b), 85.21(b).

In short, without the inclusion of § 92.101, the Proposed Rule's description of prohibited discrimination under Section 504, and thereby Section 1557, lacks established detail and is incomplete. By removing references to explanatory regulations, it injects ambiguity into Section 1557 and risks inconsistency with the discrimination actionable under Section 504.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.101 in its entirety.

B. Discrimination Based on Association (45 C.F.R. § 92.209)

DREDF also opposes HHS' unjustified elimination of 45 C.F.R. § 92.209, which prohibits discrimination on the basis of association with a protected class. Without explanation, the Proposed Rule attempts to remove this provision. However, Congress intended Section 1557 to protect against discrimination by association, and these provisions should be retained.

In the 2016 Final Rule, HHS explained that Section 1557 does not restrict "the prohibition to discrimination based on the individual's own race, color, national origin, age, disability or sex. Further, we noted that a prohibition on associational discrimination is consistent with longstanding interpretations of existing antidiscrimination laws, whether the basis of discrimination is a characteristic of the harmed individual or an individual who is associated with the harmed individual." 81 Fed. Reg. at 31439.

The current regulation's language tracks the statutory text of Title I and Title III of the Americans with Disabilities Act ("ADA"), and the regulatory language of Title II of the ADA, which protect against discrimination based on association or relationship with a person with a disability.[6] In enacting Section 1557, Congress intended to provide at least the same protections for health care consumers. In accordance with the ADA, the current regulation at 45 C.F.R. § 92.209 recognizes that people associated with a person with a disability, who may be at risk of discrimination due to their relationship with a patient, are protected under Section 1557.

If this regulation were eliminated, then a doctor could, for example, refuse to treat an individual who has an HIV-positive partner based on unfounded fears of transmission. On similar lines, a health insurer could refuse a provider's application to join a plan network if they choose to work with populations of individuals with chronic infectious diseases. Likewise, a hospital could refuse to treat a white patient because they have a biracial child, or it could exert pressure on a worried hearing parent with elementary sign language skills to interpret for her admitted Deaf child. Such inequitable and bigoted results are not what Congress intended in enacting the ACA.

By eliminating the regulatory provision expressly prohibiting discrimination on the basis of association, HHS will create uncertainty and confusion regarding the responsibilities of providers and the rights of people who experience discrimination. However, because HHS provides no explanation of its reasons for removing 45 C.F.R. § 92.209, we cannot adequately comment. We urge HHS to retain the current regulatory protections.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.209 in its entirety.

---

[6] *See* 42 U.S.C. §§ 12112(b)(4) (Title I), 12182(b)(1)(E) (Title III); 28 C.F.R. § 35.130(g) (Title II).

C. Discriminatory Benefit Design (45 C.F.R. § 92.207)

DREDF strongly opposes HHS' proposal to eliminate 45 C.F.R. § 92.207, a regulation making clear that Section 1557 prohibits covered entities from discriminating in the issuance or renewal of a health insurance policy, the coverage of a health insurance claim, cost-sharing and other coverage limitations, marketing practices, and the design of the health benefit plan. HHS' proposal to repeal this entire regulation is contrary to the text and purposes of the ACA; it would disproportionately harm people with disabilities; and it is inadequately justified in the Notice of Proposed Rulemaking ("NPRM").

In enacting the ACA, Congress intended to prohibit health insurance practices, including plan benefit designs, that discriminate on the basis of race, color, national origin, sex, age, or disability. The ACA significantly changed the health insurance industry by not only expanding access to health coverage, but also explicitly prohibiting many of the methods historically used by health insurers to minimize costs and risks. Before the ACA, the business model of health care incentivized insurers to avoid covering individuals who had high health needs or who would otherwise be costly to the plan. While there was some federal and state regulation of restrictive coverage policies, insurers still had a large array of discriminatory mechanisms at their disposal to deny enrollment, limit benefits, and impose high premiums and cost-sharing on enrollees with disabilities and pre-existing conditions.[7] The ACA ushered in a new era for health care equity—implementing reforms to expand coverage; create protections in enrollment, cost-sharing, and benefit coverage; and improve the scope and quality of health insurance.

As an integral component of these reforms, Congress mandated comprehensive health benefit coverage and explicitly prohibited discrimination in the *content* of those plan designs. Most pertinent, it prohibited limitations or exclusions of benefits based on pre-existing conditions; mandated coverage, on a nondiscriminatory basis, of ten categories of essential health benefits ("EHBs"); and prohibited qualified health plan ("QHP") "marketing practices or benefit designs that have the effect of discouraging the enrollment in such plan by individuals with significant health needs," among other protections. 42 U.S.C. §§ 300gg-3(b)(1), 18022, 18031(c)(1)(A).

Section 1557 of the ACA is the key to enforcing these statutory mandates. Section 1557 prohibits discrimination, including discrimination in the design of a benefit package, in health programs or activities receiving federal financial assistance. *See id.* § 18116(a). By statute, it creates a private right of action for individuals to enforce their civil rights in the health care context.[8] The scope of

[7] *See, e.g.*, Blake, *supra* note 1; Rosenbaum et al., *supra* note 1.

[8] *See, e.g.*, Rumble v. Fairview Health Servs., No. 14-cv-2037, 2015 WL 1197415 (D. Minn. Mar. 16, 2015) (finding that Section 1557 creates a private right of action).

actionable discrimination under Section 1557 logically covers discrimination in enrollment, equal access to benefits, and benefit design.[9]

Recognizing this statutory requirement, HHS promulgated regulations in 2016 reiterating that Section 1557 prohibits "marketing practices or benefit designs that discriminate on the basis of race, color, national origin, sex, age, or disability in a health-related insurance plan or policy." 45 C.F.R. § 92.207. In guidance, it provided examples of practices that would contravene Section 1557 and this regulation. Plans that, for example, "cover bariatric surgery in adults but exclude such coverage for adults with particular developmental disabilities;"[10] "place[e] most or all drugs that treat a specific condition on the highest cost tiers;"[11] or "exclude bone marrow transplants regardless of medical necessity"[12] would run afoul of Section 1557, it explained.

HHS' 2016 regulation logically follows the letter and intent of the ACA. Without explicit acknowledgement of and a resulting prohibition on discriminatory benefit design, Section 1557's nondiscrimination protections would be rendered illusory. By not reaching the structure of a benefit package, a health insurer could always manipulate their benefit design to elude discrimination law, despite maintaining the same discriminatory effects. For illustration, consider cancer benefits. Without the ACA reaching benefit design, a health insurer could not deny an individual with cancer enrollment in a QHP or equal access to the treatments, services, and prescription drugs the plan chooses to cover; however, it could exclude from its coverage all cancer-related surgery, chemotherapy, radiation, and post-treatment drugs. It could also limit beneficiaries to provider networks that fail to include key oncology specialists, thus avoiding coverage of the expensive treatments they may prescribe. For a person with cancer, access to a health plan would be deemed virtually meaningless in the absence of cancer-related coverage. The effect of these exclusions would be the same as an outright denial of enrollment. Elimination of the benefit design regulation perversely encourages this result. It incentivizes insurers to find roundabout ways to deter people with pre-existing conditions from their plans. This is impermissible under Section 1557 of the ACA and Section 504 of the Rehabilitation Act. *See* 29 U.S.C. § 794; 42 U.S.C. §§ 18116(a), 18031(c)(1)(A); 45 C.F.R. § 92.207(b)(2).

---

[9] *See, e.g.*, *HHS OCR Complaint RE: Discriminatory Pharmacy Benefits Design in Select Qualified Health Plans Offered in Florida* (May 28, 2014), https://healthlaw.org/resource/nhelp-and-the-aids-institute-complaint-to-hhs-re-hiv-aids-discrimination-by-fl/ (finding that placing all HIV/AIDS medications in the highest cost-sharing tier violates Section 1557).

[10] 2016 Final Rule, 81 Fed. Reg. at 31,429.

[11] HHS Notice of Benefit and Payment Parameters for 2016, 80 Fed. Reg. 10,750, 10,822 (Feb. 17, 2015).

[12] CMS CCIIO, *QHP Master Review Tools for 2015, Non-Discrimination in Benefit Design* (2015), *available at* http://insurance.ohio.gov/Company/Documents/2015_Non-Discriminatory_Benefit_Design_ QHP_Standards.pdf.

The elimination of the benefit design regulation will disproportionately harm people with disabilities, who rely on Section 1557's enforcement mechanisms to hold health insurers and health providers accountable for discriminatory practices. People with disabilities already experience significant disparities in health outcomes and access to health care.[13] For example, adults with disabilities are 58% more likely to experience obesity, three times more likely to be diagnosed with diabetes, and nearly four times more likely to have early-onset cardiovascular disease.[14] Moreover, they are nearly three times more likely to have not accessed needed health care because of cost and twice as likely to have unmet mental health needs.[15] The ACA's reforms worked to reduce some of these disparities by, for example, reducing the uninsurance rate and increasing the likelihood of a person with a disability having a regular health care provider.[16] However, there are still large gaps in health access,[17] and persistent attitudinal and programmatic barriers to care are ongoing.[18] Section 1557 provides an avenue through which people with disabilities can identify and challenge discriminatory policies—including those that manifest in the design of a health plan's benefit package. Elimination of the benefit design protections will allow health insurers to perpetuate coverage policies that exclude people with certain disabilities from benefit coverage or target the health care services, devices, and prescription drugs that people with disabilities disproportionately rely on. As a group of individuals already facing significant external barriers in the health care context, such a regression of their civil rights should not be realized.

Finally, HHS has not explained *why* it proposes to eliminate the benefit design regulation in the Proposed Rule, and it is thus impossible to provide a complete comment. The only reference to the current regulation is in Footnote 147, wherein the referenced text states that many of the current Section 1557 regulations are "duplicative of, inconsistent with, or confusing in relation to" pre-existing Section 504, Title VI, Title IX, and Age Act regulations. 84 Fed. Reg. at 27846, 27869. It is unclear which of these three factors HHS is alluding to with respect to the benefit

---

[13] *See, e.g.*, Silvia Yee, Mary Lou Breslin, et al., *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity*, NAT'L ACADS. SCI., ENG'G, & MED. (2017), *available at* http://nationalacademies.org/hmd/Activities/SelectPops/HealthDisparities/Commissioned-Papers/Compounded-Disparities.

[14] *Id.* at 32.

[15] *Id.* at 31.

[16] H. Stephen Kaye, *Disability-Related Disparities in Access to Health Care Before (2008–2010) and After (2015–2017) the Affordable Care Act*, 109 AM. J. PUB. HEALTH, no. 7, 1015–21 (July 2019); Gloria L. Krahn, *Drilling Deeper on the Impact of the Affordable Care Act on Disability-Related Health Care Access Disparities*, 109 AM. J. PUB. HEALTH, no. 7, 956–58 (July 2019).

[17] *See* Kaye, *supra* note 16, at 1019–21 (for example, across the population of people with disabilities, there has been "much greater delayed or forgone care" post-ACA).

[18] *See id.*; Yee, et al., *supra* note 13, at 31–32; 39–44.

design regulation. Regardless, concerns of duplication, inconsistency, or confusion in this context are unfounded. The benefit design regulation does not duplicate existing regulations. Section 1557 applies longstanding civil rights principles to the unique context of health care. Because pre-existing statutes such as Section 504 are more generally applicable and have not historically been applied to private health insurers,[19] their regulations do not explain how the content of a health benefit package can discriminate. *See, e.g.*, 28 C.F.R. Part 41 (HHS Section 504 regulations). Thus, it was necessary to explain this concept in the Section 1557 regulations. The benefit design regulation is also not inconsistent with or confusing in relation to pre-existing civil rights regulations. Its provisions do not contradict currently-existing regulations. Instead—in recognition that the ACA significantly reformed the health insurance market, increased administrative oversight of health plans, and applied nondiscrimination principles to private health insurers for the first time—the Section 1557 benefit design regulation served to explain one form of health insurer discrimination that was previously difficult to challenge.[20] The regulation should not be repealed on these erroneous grounds.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.207 in its entirety.

[19] Prior to the ACA, private health insurance plans did not receive FFA, and thus Section 1557 and Title VI did not typically apply to them. The ACA's creation of, e.g., premium tax credits and federal- and state-run exchanges, changed this.

[20] Prior to the ACA, private health insurers were generally not subject to disability nondiscrimination laws. Additionally, some lower courts misinterpreted *Alexander v. Choate*, 469 U.S. 287 (1985), to stand for the proposition that Section 504 does not reach the "content" of a health benefit, but rather only the ability to "access" the benefit. *See, e.g.*, Doe v. Mutual of Omaha Ins. Co., 179 F.3d 557 (7th Cir. 1999). These erroneous interpretations of *Choate* critically misunderstood the U.S. Supreme Court's holding, which made clear that people with disabilities must have "meaningful access" to health care benefits. 469 U.S. at 296–99, 301. The benefit, it explained, could not be defined in a way that disparately harms people with disabilities. *Id.* For further analysis of the meaning of *Choate* in the context of ACA-regulated health plans, *see* Brief of DREDF, DRA, DRC, DRCL, NHeLP, and ACLU as *Amici Curiae* in Support of Neither Party, Doe v. CVS Pharmacy, Inc., No. 19-15074 (9th Cir. appeal filed Jan. 1, 2019), *available at* https://dredf.org/2019/07/02/doe-v-cvs-pharmacy-inc/.

III. DISABILITY DISCRIMINATION

A. Effective Communication (45 C.F.R. § 92.202; Proposed § 92.102)

DREDF supports HHS' proposal to retain the provisions of 45 C.F.R. § 92.202 (redesignated § 92.102), regarding effective communication for individuals with disabilities. Effective communication is a critical component of accessing and receiving quality health care. DREDF often hears about entities refusing to provide effective communication or relying on communication methods that are the preference of the entity rather than the choice of the individual. Therefore, we commend HHS for holding all recipients of FFA from HHS to the higher ADA Title II standards found at 28 C.F.R. §§ 35.160–35.164. Giving primary consideration to the choice of aid or service requested by the individual with a disability helps to ensure actual effective communication and thus equal opportunity in the health care setting.

We are, however, concerned with HHS' proposed changes to the definitions relating to the effective communication regulation. First, we object generally to the deletion of the definitions at 45 C.F.R. § 92.4. The elimination of this section will cause confusion for covered entities and risk inconsistency among the various Section 1557 regulations. It also makes it more difficult to amend definitions as needed, which is especially important in the context of effective communication, as auxiliary aid technologies are constantly evolving. Second, while we appreciate HHS' efforts to incorporate many of the current ADA definitions, including the definitions of disability, auxiliary aids and services, qualified interpreter, and video remote interpreting, we note that HHS has erred in tracking the language of these longstanding definitions. The problems we have identified are as follows:

- The definition of auxiliary aids and services at proposed § 92.102(b)(1) excludes "acquisition or modification of equipment and devices" and "[o]ther similar services and actions," despite these two items being found in the ADA definition at 28 C.F.R. § 35.104 and the current Section 1557 definition at 45 C.F.R. § 92.4. HHS states in its Proposed Rule that "[t]he list of auxiliary aids and services from 28 CFR 35.104 is incorporated into the proposed rule at § 92.102(b)(1)" and in general that "[t]hese provisions are drawn from regulations implementing Title II of the Americans with Disabilities." 84 Fed. Reg. at 27866, 27867, n. 123. This list is incomplete and HHS' statements are misleading. Parts of 28 C.F.R. § 35.104 are incorporated into the Proposed Rule, but the above-quoted language regarding the "acquisition or modification of equipment and devices" and "other similar services and actions" is missing. This deletion alters what was an open-ended functional definition; it takes what is clearly a list of examples of auxiliary aids and services in the current regulations and turns it into an exhaustive list in the proposed regulation. Moreover, to the extent that HHS claims it seeks to eliminate inconsistent applications of the law, such as change is neither prudent nor consistent with the law. We strongly oppose these deletions.

- The definition of auxiliary aids and services at proposed § 92.102(b)(1) also excludes the term "Qualified" before "Interpreters" in subsection (i) and before "Readers" in subsection (ii), despite this critical adjective being found in the ADA definition at 28 C.F.R. § 35.104 and the current Section 1557 definition at 45 C.F.R. § 92.4. While we appreciate that HHS does track the content of the ADA definition of *qualified* interpreters at proposed § 92.102(b)(2)–(3), it will enable greater clarity and consistency with the ADA regulations to keep the term "Qualified interpreters" in the auxiliary aids definition at proposed § 92.102(b)(1)(i). Moreover, the word "Qualified" has also been deleted from "readers" in proposed § 92.102(b)(1)(ii), yet the proposal fails to incorporate the ADA definition of qualified readers. The change here is not merely theoretical. Covered entities should not, for example, be free to assign the task of reading personal information about healthcare status, medical procedures, and bills to a high school student hired to help with receptionist duties over the summer. The requirement for a defined "qualified reader" helps to ensure effective communication and healthcare for people with disabilities. We strongly encourage HHS to both include the word "Qualified" in proposed § 92.102(b)(1)(ii), and incorporate the ADA definition of this term, *see* 28 C.F.R. § 351.04 ("Qualified reader means a person who is able to read effectively, accurately, and impartially using any necessary specialized vocabulary.").

DREDF is also concerned with the narrowing of the "free of charge" and "timely manner" provision at proposed § 92.102(b)(2). The current Section 1557 regulations state that a covered entity must provide "appropriate auxiliary aids and services, including qualified interpreters for individuals with disabilities and information in alternate formats, free of charge and in a timely manner . . . " 45 C.F.R. § 92.8. This language echoes the ADA Title II regulations, which provide that covered entities "may not place a surcharge on a particular individual with a disability or any group of individuals with disabilities to cover the costs of measures, such as the provision of auxiliary aids or program accessibility . . . " 28 C.F.R. § 35.130(f). In proposed § 92.102(b)(2), HHS significantly narrows this provision by only stating that "*interpreting service* shall be provided to individuals free of charge and in a timely manner" (emphasis added). We strongly oppose this change and encourage HHS to replace the words "interpreting service" with "auxiliary aids and services" to be consistent with the ADA and prevent unnecessary confusion over the requirement. Covered health care entities may not legally charge for *any* auxiliary aid provided; this pre-existing legal requirement should be made clear.

Finally, HHS requests comment on whether it should add an exemption from the effective communication requirements for covered entities with fewer than 15 employees. *See* 84 Fed. Reg. at 27867. DREDF strongly opposes this exemption. HHS has not applied such an exemption in nearly 20 years and to apply it now would roll back the clock on the enforcement of effective communication for people with disabilities. To be clear, effective communication requirements profoundly impact threshold access to and the quality of health care that a person

with a disability receives. Breakdowns in communication between a health care provider and a patient with a disability are reported across all types of disabilities,[21] and the lack of accurate and effective communication can lead to misdiagnosis, erroneous treatment, and ultimately a negative impact on the health or life of the patient.[22] The lack of positive health care communication experiences can also lead to a loss of trust or fear of health care providers, leading some people with disabilities to feel as if they have no choice but to rely upon self-diagnosis and treatment.[23] The provision of appropriate auxiliary aids and services can help remedy some of these health care disparities. For example, the provision of ASL interpreters to Deaf patients preferring this type of communication accommodation has been linked with significantly higher utilization rates of preventative care, including cholesterol screens, colonoscopy, and influenza vaccines.[24] While there are still many improvements to be made, requiring all covered entities to provide effective communication is a vital first step towards ensuring health care equity.

Provider offices with fewer than 15 employees should not be exempted from this basic civil rights requirement. People with disabilities often obtain their health care from local providers or specialists with only a few employees. This is especially true in rural areas, where providers are more likely to have smaller practices, and there may only be one appropriate specialist within a reasonable distance. Small provider practices are more common than one might think: the American Medical Association's 2012–2016 Physician Practice Benchmark Survey[25] found that

---

[21] *See, e.g.*, Thilo Kroll, et al., *Primary Care Satisfaction Among Adults with Physical Disabilities: The Role of Patient-Provider Communication*, 11 MANAGED CARE Q., no. 1, 11–19 (2003); Melinda Neri & Thilo Kroll, *Understanding the Consequences of Access Barriers to Health Care: Experiences of Adults with Disabilities*, 25 DISABILITY & REHAB., no. 2, 85–96 (2003); Sara Bachman, et al., *Provider Perceptions of Their Capacity to Offer Accessible Health Care For People With Disabilities,* 17 J. DISABILITY POL'Y STUD., no. 3, 130–36 (2006); Elizabeth H. Morrison, et al., *Primary Care for Adults with Physical Disabilities: Perceptions from Consumer and Provider Focus Groups*, 40 FAM MED., no. 9, 645–51 (2008).

[22] *See* Yee, et al., *supra* note 13, at 43–44 (summarizing and analyzing the abundance of research on this point).

[23] *Id.*

[24] Michael M. McKee, et al., *Impact of Communication on Preventive Services Among Deaf American Sign Language Users*, 41 AM. J. PREVENTATIVE MED., no. 1, 75–79 (2011).

[25] Carol K. Cane, AM. MED. ASSOC., *Policy Research Perspectives: Updated Data on Physician Practice Arrangements: Physician Ownership Drops Below 50 Percent* 4–5 (2017), *available at* https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/public/health-policy/PRP-2016-physician-benchmark-survey.pdf. The Benchmark surveys are of practicing physicians who provide a minimum of 20 hours of patient care per week in one of the 50 states or the District of Columbia and who are not employed by the federal government.

a majority of physicians still work in small practices, with 57.8% working in practices of 10 or fewer physicians and 37.9% working in practices with fewer than 5 physicians.[26] Physicians in single-specialty practices were even more likely to be in small practices.[27] Exempting these smaller practices means that people with disabilities will have significantly more difficulty obtaining effective communication from both general and specialty physicians, and it sends the message that HHS' latest healthcare-specific civil rights regulations make it harder for people with communication disabilities to obtain needed health care. This exemption could thus function to exclude many people with disabilities from accessing the health care they need. Congress surely did not intend such a result in enacting the ACA and Section 1557.

Moreover, in practice, this exemption would make little sense because public accommodations (including hospitals and provider offices) of any size are already required to provide effective communication under Title III of the ADA. Even HHS, when it originally announced that the 15-employee exemption does not apply to entities receiving HHS funds, recognized this reality:

> This is not a new requirement; Title III of the Americans with Disabilities Act (ADA) already requires public accommodations of all sizes to provide auxiliary aids and services to persons with disabilities where necessary to ensure effective communication and Title II of the ADA extends the same requirement to state and local government entities. The vast majority of entities that receive federal financial assistance from HHS thus are already required to provide auxiliary aids and services to persons with disabilities where necessary to ensure effective communication.[28]

If HHS' intent is to protect small entities from costs, then the appropriate mechanisms to do so is already in 45 C.F.R. § 92.202, which incorporates the ADA Title II exemptions found in 28 C.F.R. § 35.164 by explicit reference.[29] Adding an exemption for small entities will harm people with disabilities and is not the proper solution.

---

[26] A practice with 10 physicians may or may not have 15 or fewer employees, but a practice with 5 physicians is very likely to have fewer than 15 employees. *Id.*

[27] *Id.*

[28] HHS OCR, Section 504 of the Rehabilitation Act of 1973; Notice of Exercise of Authority Under 45 CFR 84.52(d)(2) Regarding Recipients With Fewer Than Fifteen Employees, 65 Fed. Reg. 79368, 79368 (Dec. 19, 2000).

[29] 28 C.F.R. § 35.164 ("This subpart does not require a public entity to take any action that it can demonstrate would result in a fundamental alteration in the nature of a service, program, or activity or in undue financial and administrative burdens. In those circumstances where personnel of the public entity believe that the proposed action would fundamentally alter the service, program, or activity or would result in undue financial and administrative burdens, a

RECOMMENDATIONS:

- HHS should clarify that the list of auxiliary aids and services in proposed 45 C.F.R. § 92.102(b)(1) is not exhaustive by adding the following after subsection (ii):

  "(iii) Acquisition or modification of equipment and devices; and

  (iv) Other similar services and actions."

- HHS should put back the term "Qualified" before "Interpreters" in proposed 45 C.F.R. § 92.102(b)(1)(i) and before "Readers" in proposed 45 C.F.R. § 92.102(b)(1)(ii), and it should incorporate the definition of "Qualified readers" found at 28 C.F.R. § 35.104.

- The requirement to provide services "free of charge and in a timely manner" in proposed 45 C.F.R. § 92.102(b)(2) should be applied to all "auxiliary aids and services," not just "interpreter services."

- No exemption should be added for covered entities with fewer than 15 employees.

B. Information and Communication Technology (45 C.F.R. § 92.204; Proposed § 92.104)

DREDF supports HHS' proposal to retain the provisions of 45 C.F.R. § 92.204 (redesignated § 92.104), regarding information and communication technology ("ICT") for individuals with disabilities. Like effective communication, access to information, communication, and electronic technologies is important to guaranteeing people with disabilities equal access to health care services—and this fact is even more true as U.S. society increasingly relies on digital and web-based communications. Health care providers and health insurance plans are rapidly developing interactive websites, moving their medical recordkeeping online, and communicating with patients through electronic means. We commend HHS' efforts to ensure that people with disabilities are not left behind as technologies evolve.

We are, however, concerned with HHS' proposed change to the definition of "information and communication technology" in proposed § 92.104(c). While we generally object to the elimination of the definitions at 45 C.F.R. § 92.4, we do appreciate that HHS has incorporated the definition of ICT from the U.S. Access Board regulations implementing Section 508 of the Rehabilitation Act. We note, however, that a critical phrase was removed from the U.S. Access Board's definition. The second sentence of the U.S. Access Board's definition reads: "Examples of ICT include, but are not limited to: . . ." (emphasis added). 36 C.F.R. Part 1194, Appendix A, E103.4.

---

public entity has the burden of proving that compliance with this subpart would result in such alteration or burdens.").

HHS has removed the phrase "but are not limited to" in its Proposed Rule. We strongly encourage HHS to keep this phrase. Information and communication technologies are constantly evolving; it is difficult to predict what technologies will be in place in 5, let alone 10 or 20, years. In order to maintain flexibility and ensure that the regulations keep pace with emerging technologies, HHS should make it absolutely clear that its list of examples of ICT is not exhaustive.

Finally, HHS requests comment on whether it should cross-reference Section 508 and its applicable implementing regulations in proposed § 92.104. *See* Fed. Reg. at 27867–68. DREDF supports this proposal. Cross-referencing Section 508 and its regulations will help ensure that the Section 1557 stay up-to-date as the Section 508 regulations are amended, and it will ensure consistency across the civil rights laws.

RECOMMENDATIONS:

- HHS should amend the second sentence of proposed 45 C.F.R. § 92.104(c) to read "Examples of ICT include, <u>but are not limited to</u>: . . .".
- HHS should cross-reference Section 508 and its applicable implementing regulations in proposed 45 C.F.R. § 92.104.

C. Architectural Standards (45 C.F.R. § 92.203; Proposed § 92.103)

DREDF supports HHS' proposal to retain the provisions of 45 C.F.R. § 92.203 (redesignated § 92.103), regarding accessibility standards for buildings and facilities. We support HHS' position that the 2010 ADA Standards for Accessible Design ("2010 Standards") are the appropriate architectural standards for any facility or part of a facility in which health programs or activities are conducted that is constructed or altered by or on behalf of, or for the use of, a recipient or State Exchange. We appreciate HHS' continued commitment to ensuring that health care facilities and provider offices are accessible for people with disabilities.

HHS requests comment on the appropriateness of applying the 2010 ADA Standards' definition of "public building or facility" (i.e., the ADA Title II standards) to all entities covered under Section 1557, specifically with respect to multistory building elevators and text telephone ("TTY") requirements. *See* Fed. Reg. at 27867. DREDF responds that it is indeed appropriate and *necessary* to hold all health programs and activities that receive federal financial assistance to these higher Title II standards, and we strongly oppose importing the private multistory building exception found at Section 206.2.3 of the 2010 Standards and the private entity TTY standard found at Section 217.4.3 of the 2010 Standards into Section 1557.

First, by virtue of accepting federal financial assistance from HHS, it is entirely appropriate to hold <u>all</u> covered health programs and activities, including private entities, to the Title II standards.

If we look at the ADA in a vacuum, a private entity that operates as a place of public accommodation would only be subject to the lower Title III architectural standards. However, here, the ADA standards function in relation to Section 1557, which notably references and incorporates the grounds of discrimination of Section 504, not the ADA. Section 504 covers programs and activities receiving federal financial assistance. So, in this context, some private health care practices, for example, would be on the hook for not only being a public accommodation under Title III, but also an entity that avails itself to nondiscrimination law (Section 504 and Section 1557) by virtue of choosing to accept federal financial assistance from HHS. This distinction justifies holding private health care entities to a higher standard, which even HHS itself recognized in its 2015 proposed rule:

> [The] entities covered under the proposed rule are health programs and activities that either receive Federal financial assistance from HHS or are conducted directly by HHS. Although OCR could apply Title II standards to States and local entities and Title III standards to private entities, we believe it is appropriate to hold all recipients of Federal financial assistance from HHS to the higher Title II standards as a condition of their receipt of that assistance.[30]

Additionally, it is important to consider the context of the buildings and facilities at issue under Section 1557. While we affirm that architectural access is essential in all contexts, we note that it is particularly crucial for people with disabilities to have equal access to health programs and activities. People with disabilities already face significant barriers in accessing needed health care,[31] and exempting a health insurance enrollment center or plan benefit counselor from having an elevator or a small health care practice from providing TTY, for example, will only serve to widen the disparities in health access. By choosing to operate a business that is critical to an individual's health and life, and then by choosing to accept HHS funds, private health entities have also assumed a duty to ensure that their buildings and facilities are accessible for all. These are also obligations that are inevitably included in the contracts that health entities enter into when they agree to function as a plan or provider with Medicaid, Medicare, or through an Exchange. Watering down this responsibility is unacceptable and unlawful. It will function to reward those few construction or alteration projects that did not have the foresight to take into account the needs of healthcare consumers with disabilities.

As to the two exemptions that HHS specifically requests comment on, DREDF strongly opposes them both. Section 206.2.3 of the 2010 Standards provides, in relevant part, that "[i]n private buildings or facilities that are less than three stories or that have less than 3000 square feet (279 m^2) per story, an accessible route shall not be required to connect stories provided that the building or facility is not . . . the professional office of a health care provider . . . or another type

[30] 2015 Proposed Rule, 80 Fed. Reg. at 54186.

[31] *See, e.g.*, Yee, et al., *supra* note 13; Kaye, *supra* note 16.

of facility as determined by the Attorney General." This private elevator exemption dates back to the 1991 ADA Standards for Accessible Design, a time period in which the concept of widespread architectural accessibility was still relatively recent and wherein the construction or addition of accessible elevators was still considered extremely burdensome and costly. Today, private entities have had over 50 years[32] to adjust their architectural designs and consider the needs of people with disabilities. No longer is requiring a multi-story building or facility to have an elevator the foreign concept or perceived burden it once was. Instead, it is required by the law. Rolling back the standards for having an elevator in private health buildings will only serve to erect a new, additional barrier for individuals with disabilities to access needed health programs.

DREDF also opposes lowering the private entity TTY standard. Section 217.4.3 of the 2010 Standards provides, in relevant part, that "[w]here at least one public pay telephone is provided in a *public building*, at least one public TTY shall be provided in the building" (§ 217.4.3.1) and "[w]here four or more public pay telephones are provided in a *private building*, at least one public TTY shall be provided in the building" (§ 217.4.3.2). The lower 4:1 TTY standard for private entities, which originated 15 years ago,[33] is now outdated given the current widespread availability and affordability of the technology. It takes little effort or cost for covered entities to provide 1:1 TTY, yet the benefits offered to people who are Deaf or have hearing impairments are significant. Although TTY is not as commonly used as it once was, there are certain populations that still rely on TTY, including people who are DeafBlind, people living in rural areas, and senior citizens. For these individuals, TTY critically enables communication with their health care providers, their insurance companies, and other similar entities. Accordingly, HHS should not lower the 1:1 TTY standard for private health care entities.

We also encourage HHS to explicitly incorporate standards that require covered entities to accommodate newer communication technologies that are being used by people with disabilities. Since the establishment of the TTY standards, new innovations such as real-time text ("RTT") have emerged. We urge HHS to codify language that both retains the existing TTY ratios and also adopts similar RTT ratios,[34] in order to be inclusive of modern technologies. Like TTY, all health care entities should be held to more stringent public entity RTT ratios. This

[32] The Architectural Barriers Act, the first federal law requiring that facilities designed, constructed, altered, or leased with certain federal funds be accessible for people with disabilities, was signed into law in 1968. *See* 42 U.S.C. §§ 4151–57.

[33] The 4:1 private TTY standard was first adopted in the 2004 ADA Accessibility Guidelines ("ADAAG").

[34] The Federal Communications Commission has adopted rules to facilitate a transition from TTY technology to RTT technology, which HHS could look to for guidance. *See* 47 C.F.R. Part 67.

addition will help ensure that the Section 1557 regulations stay up-to-date with technological developments.

RECOMMENDATIONS:

- HHS should continue to apply the 2010 ADA Standards' definition of "public building or facility" to all entities covered under Section 1557.
- HHS should not incorporate the private multistory building elevator exemption into Section 1557.
- HHS should not lower the 1:1 TTY ratio for private entities under Section 1557. It should retain the existing TTY ratios and also adopt stringent RTT ratios.

D. Medical Diagnostic Equipment Standards

DREDF further recommends that HHS reference and incorporate the U.S. Access Board's Standards for Accessible Medical Diagnostic Equipment, published at 36 C.F.R. Part 1195, into 45 C.F.R. § 92.203 (as redesignated § 92.103).

In its 2016 Final Rule, HHS considered but ultimately declined to adopt specific language regarding accessibility standards for medical diagnostic equipment into Section 1557. *See* 81 Fed. Reg. at 31422. It explained that "the United States Access Board is currently developing standards for accessible medical diagnostic equipment and, therefore, we are deferring proposing specific accessibility standards for medical equipment." *Id.* HHS OCR has further made clear that "[o]nce the United States Access Board standards are promulgated, OCR intends to issue regulations or policies that require covered entities to conform to those standards." 80 Fed. Reg. at 54187.

On January 9, 2017, the U.S. Access Board finalized and published its comprehensive Standards for Accessible Medical Diagnostic Equipment.[35] Thus, it is now appropriate and necessary to incorporate these standards into the Section 1557 regulations. Specifically, we recommend that 45 C.F.R. § 92.203 (redesignated § 92.103) incorporate a subsection as follows:

> (a) If a facility or part of a facility in which health programs or activities are conducted purchases or replaces medical diagnostic equipment on or after [30 DAYS FROM DATE OF PUBLICATION OF FINAL RULE], then such newly-acquired equipment

[35] ATBCB, *Standards for Accessible Medical Diagnostic Equipment: Final Rule*, 82 Fed. Reg. 2810 (Jan. 9, 2017) (codified at 36 C.F.R. Part 1195).

shall comply with the 2017 Standards for Accessible Medical Diagnostic Equipment at 36 CFR part 1195.

(b) Each facility or part of a facility in which health programs or activities are conducted shall fully comply with the 2017 Standards for Accessible Medical Diagnostic Equipment at 36 CFR part 1195 by or before [24 MONTHS FROM DATE OF PUBLICATION OF FINAL RULE].

While we recognize that HHS must still develop scoping requirements for these standards and that this process will take time, we emphasize that this development process should begin now and, while the Section 1557 regulations are being otherwise amended, the U.S. Access Board standards should be codified. DREDF is deeply aware of the degree to which the common lack of accessible medical equipment presents grave barriers to effective healthcare for people with mobility, strength, and other disabilities.[36] Now that we have comprehensive, vetted standards to combat these widespread access barriers, HHS should take steps to require health care facilities to follow them.

RECOMMENDATION: At 45 C.F.R. § 92.203 (redesignated § 92.103), HHS should incorporate the follow subsection:

(a) If a facility or part of a facility in which health programs or activities are conducted purchases or replaces medical diagnostic equipment on or after [30 DAYS FROM DATE OF PUBLICATION OF FINAL RULE], then such newly-acquired equipment shall comply with the 2017 Standards for Accessible Medical Diagnostic Equipment at 36 CFR part 1195.

(b) Each facility or part of a facility in which health programs or activities are conducted shall fully comply with the 2017 Standards for Accessible Medical Diagnostic Equipment at 36 CFR part 1195 by or before [24 MONTHS FROM DATE OF PUBLICATION OF FINAL RULE].

E. Reasonable Modifications (45 C.F.R. § 92.205, Proposed § 92.105)

DREDF supports HHS' proposal to retain the provisions of 45 C.F.R. § 92.205 (redesignated § 92.105), regarding covered entities' requirement to make reasonable modifications to policies, practices, or procedures. This language of "reasonable modification" conforms to other nondiscrimination regulations that apply to state and local governments and public

[36] *See, e.g.*, Nancy M. Mudrick, Mary Lou Breslin, et al., *Physical Accessibility in Primary Health Care Settings: Results from California On—Site Reviews*, 5 DISABILITY & HEALTH J. 159–67 (2012); Tara Lagu, et al., *Access to Subspecialty Care for Patients with Mobility Disabilities: A Survey*, 158 ANN. INTERN. MED., no. 6, 441–46 (2013).

accommodations (including hospitals and medical providers), and therefore it is consistent with other regulatory schemes that are already applicable to many covered entities. The 2016 Final Rule specifically applies the definition of "reasonable modification" from Title II of the ADA (state and local governments), which we believe continues to be the appropriate standard for recipients of federal financial assistance, programs established under Title I of the ACA, and programs administered by HHS. The concept of "reasonable modification" is not burdensome. It has long applied to a broad swath of entities, whether public or private, and it is therefore clear and familiar to most entities covered under Section 1557.[37] There is no reason to make any changes to this language, nor to import unrelated concepts from other regulatory schemes.

HHS has, however, requested comment on whether the following language should be substituted for the proposed 45 C.F.R. § 92.105: covered entities shall make "reasonable accommodation to known physical or mental limits of an otherwise qualified" individual with a disability. HHS also asks whether an exemption for "undue hardship" should be imported from 45 C.F.R. § 84.12 and 28 C.F.R. § 92.205 into proposed 45 C.F.R. § 92.105. The answer to both questions is no. HHS should not make any changes to the language at current 45 C.F.R. § 92.205.

As a preliminary matter, in asking about the imported language, HHS states that the language is taken from HHS Section 504 regulations and the "Department of Justice's Section 504 coordinating regulation." *See* 84 Fed. Reg. at 27868. However, both citations to the DOJ Section 504 coordinating regulations are to a non-existent portion of the Code of Federal Regulations.[38] These incorrect citations makes it impossible for the public to know with certainty what HHS is proposing, and it does not allow the public to analyze the context of the proposed imported

[37] *See, e.g.,* 28 C.F.R. § 35.130(b)(7) (ADA Title II regulation) ("A public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity."). Title III also incorporates a requirement that covered entities make "reasonable modifications in policies, practices, or procedures, when the modifications are necessary to afford goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities, unless the public accommodation can demonstrate that making the modifications would fundamentally alter the nature of the goods, services, facilities, privileges, advantages, or accommodations." *Id.* § 36.302(a).

[38] *See* 2019 Proposed Rule, 84 Fed. Reg. at 27868 (citing to 28 C.F.R. § 92.205 two separate times). 28 C.F.R. Part 92 contains regulations regarding the "Office of Community Oriented Policing Services (COPS)," and does not contain a § 92.205.

language or any case law interpreting such language.[39] Public comment requires transparency, and the source of any imported language is an integral part of transparency.

New exemptions to the reasonable modification requirement are unnecessary and contrary to Section 1557. The concept of a "reasonable modification" is not boundless—it is already well-defined by regulation and decades of case law. In fact, the definition of "reasonable modification" is so clear that HHS declined to provide additional explanation of the term in the 2016 Final Rule.[40] The current regulations track Title II of the ADA, requiring covered entities to make a reasonable modification "unless the covered entity can demonstrate that making the modifications would fundamentally alter the nature of the health program or activity." 45 C.F.R. § 92.205. Continuing to apply the "reasonable modification" analysis to Section 1557 is logical and promotes consistency with pre-existing civil rights statutes, one of HHS' stated goals of their NPRM. 84 Fed. Reg. at 27848. Neither Section 504 nor Title II of the ADA would permit an exemption for "undue hardship" in this context, and it is inappropriate to import such an exemption into Section 1557 where none exists in the statute itself.

Further, the suggested imported language of "reasonable accommodation," "known physical or mental limitation," and "undue hardship" comes directly from *employment*-related regulations, which are a distinct and specialized context. Such concepts are ill-fitting for health programs and activities, and they cannot be applied under Section 1557. For example, the definition of "undue hardship" makes little sense outside of the employment context, as it requires consideration of factors often irrelevant to health care, such as "(1) The overall size of the recipient's program or activity with respect to number of employees, number and type of facilities, and size of budget; (2) The type of the recipient's operation, including the composition and structure of the recipient's workforce; and (3) The nature and cost of the accommodation needed." *See* 45 C.F.R. § 84.12. These factors make sense for employers; they do not when applied to health care. For instance, the composition and structure of a workforce and the number of employees is relevant to common employment-related accommodations, such as changes in job duties or schedules—

[39] It appears that HHS seeks to import DOJ's rules for the implementation of Executive Order 12250. *See* 28 C.F.R. § 41.53. It is also possible that HHS intends to refer to DOJ's rules for reasonable accommodation in employment in federally assisted programs pursuant to Section 504. *See id.* § 42.511. Either way, it is incumbent on HHS to accurately explain the source of any regulations it seeks to substitute.

[40] *See* 81 Fed. Reg. at 31382 ("OCR believes that defining the terms ''reasonable modification'' and ''accessibility'' in this rule is unnecessary, given the meaning that these terms have acquired in the long history of enforcement of Section 504 and the ADA in the courts and administratively. We intend to interpret both terms consistent with the way that we have interpreted these terms in our enforcement of Section 504 and the ADA and so decline to add these definitions to the final rule.").

but these factors are much less likely to have a bearing on common health care modifications, which may more commonly include requests for alternative evacuation plans for individuals who cannot use stairs, additional training for health care staff on how to provide services to certain individuals, ensuring lab referrals are made to accessible entities when necessary, or altering a policy to allow an individual to remain in a wheelchair and avoid unnecessary transferring while receiving treatment such as dental care. Because the factors used to analyze "undue hardship" are more appropriate for the employment context, we believe that the appropriate approach is to retain the "reasonable modification" language, which is taken from Title II of the ADA, already applies to many entities subject to Section 1557, and has a clear definition that is flexible enough to provide guidance to health care entities.

We also object to the importation of the concept of "known physical or mental limitation." This addition will introduce confusion, suggest to covered entities that their obligations are limited, and create an undue focus on the measures that entities must take in response to requests for modifications. Disability discrimination encompasses not just inappropriate responses to requests for modifications, but also a failure of covered entities to take affirmative steps to prevent discrimination and provide needed reasonable accommodations and policy modifications. Taken in conjunction with the proposed deletion of 45 C.F.R. § 92.101, which defines discriminatory actions prohibited (discussed *supra,* Section II.A), importing the language regarding "known physical or mental limitation" could be read to limit covered entities' obligations. Nothing in Section 1557 permits such limitations, and such an importation would be contrary to the language of Section 1557 and the larger statute within which it sits. HHS has provided no explanation of how this concept, which heretofore has been largely limited to the employment context where daily contact and exposure to an employee's accommodation needs would be far more prevalent, would be applied in the health care context. Its application would undermine HHS' stated purpose of the Proposed Rule, which is to promote consistency in the application of rules and to adhere to the enforcement mechanisms available in the underlying statutes. *See* 84 Fed. Reg. at 27849–51.

Furthermore, while we disagree with HHS' statement that Congress only intended to permit disparate impact claims if such claims were permissible prior to Section 1557, HHS admits that many courts have permitted disparate impact claims under Section 504.[41] Importing language regarding "known" limitations could be interpreted as limiting plaintiffs' ability to bring systemic disparate impact claims or other substantive claims. If HHS intends to create such limitations, it must be explicit about its intent and do so via a transparent rulemaking process.

[41] *See, e.g.,* McWright v. Alexander, 982 F.2d 222, 229 (7th Cir. 1992); Smith v. Barton, 914 F.2d 1330, 1340 (9th Cir. 1990).

For the foregoing reasons, we urge HHS to retain the language in proposed 45 C.F.R. § 92.105 as drafted and to not import any new exemptions or language regarding "reasonable accommodations for known physical and mental impairments."

RECOMMENDATIONS:

- HHS should retain the current language of "reasonable modification" at 45 C.F.R. § 92.205 (redesignated § 92.105).
- HHS should not import an "undue hardship" exemption, or language of "known physical or mental limitation," into the regulations related to reasonable modifications under Section 1557.

F. Request for Comment on Proposed 45 C.F.R. §§ 92.102–.105

HHS requests comment on whether it has struck the "appropriate balance" in proposed 45 C.F.R. §§ 92.102 through 92.105, with respect to Section 504 rights and obligations imposed on the "regulated community." *See* 84 Fed. Reg. at 27868. DREDF generally agrees that, to the extent that HHS has retained protections from the 2016 Final Rule, such protections are appropriate. However, to the extent that the proposal deviates from the current regulations, as explained in detail in the previous subsections, we are extremely concerned that people with disabilities and their families will be disproportionately harmed.[42] Additionally, we are troubled with HHS' question and its underlying assumption. The role of an Executive agency is not to evaluate "whether the benefits of these provisions exceeds the burdens imposed by them." *See* 84 Fed. Reg. at 27868. Such a balancing exercise is not called for by the ACA or the Administrative Procedures Act ("APA"), and it inserts an inappropriate level of regulatory finesse on a remedial scheme that was created by Congress and broadly intended to correct decades of harm and health care disparities.[43] The task of an Executive agency is to interpret and implement the enabling statute. The proposed balancing of interests may be an appropriate role for Congress, but it is not for the administrative branch. We thus disagree with the premise of this question.

HHS also generally asks whether the Section 1557 regulations are consistent with the regulatory scheme for entities that are not covered under Section 1557 (such as human services grantees), or whether underlying regulations for other civil rights statutes need to be modified. In previous

[42] *See supra* notes 13–20 and accompanying text.

[43] *See, e.g.*, 42 U.S.C. § 12101 (ADA findings and purposes). The ADA built upon Section 504, and Section 1557 follows in their footsteps. *See also* Kang v. U. Lim Am., Inc., 296 F.3d 810, 816 (9th Cir. 2002); H.R. REP. NO. 102–40, pt. 1, at 88 (1991), *reprinted in* 1991 U.S.C.C.A.N. 549, 626 (stating that "remedial statutes, such as civil rights law[s], are to be broadly construed").

sections, we have commented on areas where it is inappropriate to import regulations created for other contexts into Section 1557's regulatory scheme. While there are clearly other areas of nondiscrimination law where importing or exporting other regulatory regimes would be inappropriate, HHS has not provided sufficient clarity or specificity in its questions or their context in order to allow us to provide additional meaningful comment outside of our statements above.

Pursuant to the APA, if HHS proposes changes to existing regulations, then it must provide its own justification for these proposed revisions. Then, the public must be provided an opportunity to comment on HHS' explanations and perceived rationales for these changes. HHS' attempt to solicit feedback on unspecified underlying regulations that it may then use to promulgate unanticipated changes in a Final Rule violates the APA and its long-established procedures for notice and comment rulemaking. These questions would be more appropriately posed prior to the agency issuing an NPRM, such as through a Request for Information ("RFI"). We thus decline to provide additional feedback on the question of whether Section 1557 is generally aligned with underlying but unspecified regulations, but we have provided our explanations, justifications, and supporting evidence for our comments in the sections above.

IV. SEX AND LGBTQI DISCRIMINATION

A. Sex and LGBTQI Discrimination under Section 1557 (45 C.F.R. §§ 92.4, 92.206, 92.207)

DREDF stands with our LGBTQI allies in opposing HHS' proposal to eliminate 45 C.F.R. §§ 92.4 and § 92.206, which define sex discrimination under Section 1557 to include discrimination on the basis of gender identity, sex stereotyping, pregnancy, false pregnancy, termination of pregnancy or recovery therefrom, or childbirth or related medical conditions; as well as § 92.207, which specifically prohibits discrimination against transgender individuals in health care coverage, including coverage of gender-affirming health care services.

Sex discrimination in health care has a disproportionate impact on women of color, women with disabilities, LGBTQI people, and individuals living at the intersections of multiple identities—resulting in them paying more for health care, receiving improper diagnoses at higher rates, being provided less effective treatments, and sometimes being denied care altogether. For example, a recent nationwide study of nearly 30,000 transgender individuals found that transgender people with disabilities are significantly more likely to have negative experiences with health care providers; face discrimination in the health care and social service setting; and experience cost-of-care barriers.[44] Social determinants of health, including economic instability, housing access, negative educational experiences, and poor social environment, are also markedly negative for people with transgender and disability identities.[45]

As the first broad prohibition against sex discrimination and intersectional discrimination in health care, Section 1557 is crucial to ending discrimination against historically marginalized groups in the health care industry. The current regulations make clear that sex discrimination correctly includes discrimination based on gender identity, sex stereotyping, and termination of pregnancy, among other factors. *See* 45 C.F.R. §§ 92.4, 92.206. The Proposed Rule attempts to roll back these integral protections. Although HHS acknowledges in the preamble to the NPRM that Title IX prohibits discrimination based on pregnancy, including termination of pregnancy, it refuses to state whether HHS would enforce those protections. The scope of statutory protection

[44] S.E. James, et al., *The Report of the 2015 U.S. Transgender Survey*, NAT'L CTR. FOR TRANSGENDER EQUALITY (Dec. 2017), https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf; *Health Disparities at the Intersection of Disability and Gender Identity: A Framework and Literature Review*, DISABILITY RIGHTS EDUCATION & DEFENSE FUND (July 2018), *available at* https://dredf.org/wp-content/uploads/2018/07/Health-Disparities-at-the-Intersection-of-Disability-and-Gender-Identity.pdf.

[45] NCTE, *supra* note 44; DREDF, *supra* note 44.

under Section 1557 is clear, however, without unambiguous implementing regulations and enforcement, illegal discrimination is likely to flourish.

The elimination of the sex discrimination regulations at 45 C.F.R. §§ 92.4, 92.206, 92.207 would disproportionately harm LGBTQI people, and especially transgender, nonbinary, and gender nonconforming people, who already face unique barriers to accessing care, such as high uninsurance rates, discrimination and harassment.[46] Under the Proposed Rule, those barriers would only increase. For example, transgender, nonbinary, and gender nonconforming people assigned female at birth whose gender marker is male or nonbinary could be denied coverage for needed ongoing preventative care such as a pap smear or mammogram. Similarly, transgender nonbinary and gender nonconforming people assigned male at birth whose gender marker is female or nonbinary could be denied coverage for necessary care, such as a prostate exam. These discriminatory barriers to care will further compound when an LGBTQ individual also has a disability. For example, because of the common lack of equipment accessibility, people with disabilities are significantly less likely to be current with their pap test and mammogram.[47] It is easy to see how these barriers, when combined with weakened sex-based discrimination protections, will disproportionately harm LGBTQI people with disabilities.

The Proposed Rule would also disproportionately impact women, people of color who are pregnant, and women with disabilities, especially those living in rural areas. Women of color already face unique barriers to accessing pregnancy-related and/or abortion care, such as a discrimination, harassment, refusals of care, and high rates of pregnancy-related complications. For example, Asian American and Pacific Islander women are two times as likely to die from pregnancy-related causes than white women, Black women are three to four times more likely to die from pregnancy related complications than white women, and Native American women are more than four times more likely to die during or immediately after pregnancy than white women. Likewise, people who are pregnant and have disabilities face significant barriers to reproductive health care that are attitudinal in nature. Health care providers often regard women with disabilities as “childlike” and “asexual.”[48] Negative assumptions about their capacity or desire to have children are widespread and can result in sub-standard pregnancy and

[46] *See* NCTE, *supra* note 44.

[47] Yee, et al., *supra* note 13, at 31.

[48] Yee, et al., *supra* note 13, at 44 (citing Kenneth L. Robey, et al., *Implicit Infantilizing Attitudes About Disability*, 18 J. DEVELOPMENTAL & PHYSICAL DISABILITY, no. 4, 441–53 (2006); NATIONAL COUNCIL ON DISABILITY, *The Current State of Health Care for People with Disabilities* (Washington, DC: National Council on Disability) (2009); Maureen S. Milligan & Aldred H. Neufeldt, *The Myth Of Asexuality: A Survey Of Social And Empirical Evidence*, 19 SEXUALITY & DISABILITY, no. 2, 91–109 (2001); Tom Shakespeare, *Disabled Sexuality: Toward Rights and Recognition*, 18 SEXUALITY & DISABILITY, no. 3, 159–66 (2000)).

reproductive care. The sexual health of women with intellectual disabilities is particularly neglected, leading to disparate rates of breast and cervical cancer screenings.[49] A rollback in Section 1557's sex discrimination protections will only serve to widen these health care disparities.

Further, the proposed incorporation of Title IX's exemptions is unlawful and would cause further harm to LGBTQI people, women of color, and LGBTQI and/or women with disabilities. For example, the Proposed Rule impermissibly tries to add Title IX's religious exemption to Section 1557's protection against sex discrimination, which could embolden providers to invoke personal beliefs to deny access to a broad range of health care services, including birth control, sterilization, certain fertility treatments, abortion, and gender-affirming care. Similarly, the proposal attacks abortion access by impermissibly incorporating the "Danforth Amendment," which carves out abortion care and coverage from the ban on discrimination of sex in the education context. Both attempts to incorporate exemptions from other laws violate the plain language of Section 1557 and should not be codified.

RECOMMENDATIONS:

- HHS should retain 45 C.F.R. §§ 92.4, 92.206, 92.207 in their entirety.
- HHS should not incorporate Title IX's religious and abortion exemptions.

B. LGBTQI Discrimination in Other Contexts

In addition to HHS' proposals to weaken LGBTQI rights under Section 1557 of the ACA, HHS also proposes to rollback protections against sexual orientation and gender identity discrimination across all HHS health care regulations. DREDF strongly opposes this proposal.

The 2016 Final Rule implementing Section 1557 did not touch other HHS regulations. The Proposed Rule, for the first time, now attempts to erase all references to gender identity and sexual orientation across a wide range of HHS administered and/or financially assisted programs

[49] Yee, et al., *supra* note 13, at 44 (citing Nechama Greenwood & Joanne Wilkinson, Sexual and Reproductive Health Care for Women with Intellectual Disabilities: A Primary Care Perspective, 2013 INT'L J. FAMILY MED. 1–8 (2013); Joshua A. Salomon, et al., *Common Values in Assessing Health Outcomes from Disease and Injury: Disability Weights Measurement Study for the Global Burden of Disease Study 2010*, 380 LANCET, no. 9859, 2129–43 (2012); Judith K. Barr, et al., *Understanding Barriers to Participation in Mammography by Women with Disabilities*, 22 AM. J. HEALTH PROMOTION., no. 6, 381–85 (2008); Susan M. Havercamp & Haleigh M. Scott, *National Health Surveillance of Adults with Disabilities, Adults with Intellectual and Developmental Disabilities, and Adults with No Disabilities*, 8 DISABILITY HEALTH J., no. 2, 165–72 (2015)).

and activities, including private insurance and education programs. If this proposal were codified, it would significantly weaken the health care rights of already-disadvantaged groups and serve to widen disparities in access to health care and health outcomes across the country.

Prior to the passage of the ACA, being transgender was treated as a "pre-existing condition." As a result, transgender people, like people with pre-existing disabilities, could not find affordable health insurance coverage. Under the Proposed Rule, states and Marketplaces could again discriminate against LGBTQI people in their eligibility determinations and enrollment periods; agents and brokers who assist with marketplace plans could discriminate in enrollment; and health insurance issuers could discriminate in their health care benefit design, marketing practices, plan premiums, or coverage decisions.

Additionally, if this Proposed Rule were codified, Medicaid managed care entities and state Medicaid programs could be emboldened to discriminate against LGBTQI beneficiaries. LGBTQI people are more likely to live in poverty than the overall U.S. population.[50] As a result, they are also more likely that non-LGBTQI people to use Medicaid.[51] Within LGBTQI communities, LGBTQ people of color (24%) are more likely than white LGBTQ people (18.8%) to receive Medicaid; transgender people (21.4%) are more likely than LGBQ cisgender people (13.4%) to receive Medicaid; and LGBTQ people with disabilities (44.4%) are more likely than LGBTQ people with no disabilities (11.8%) to receive Medicaid.[52] The Proposed Rule would impermissibly open the door to discrimination against the many LGBTQI people enrolled in Medicaid programs across the country.

---

[50] *See*, *e.g.*, INTERSECTING INJUSTICE: A NATIONAL CALL TO ACTION (Lourdes Ashely Hunter, Ashe McGovern & Carla Sutherland eds., 2018), *available at* http://socialjusticesexuality.com/intersecting_injustice/.

[51] Caitlin Rooney, et al., *Protecting Basic Living Standards for LGBTQ People*, CTR. FOR AM. PROGRESS (Aug. 13, 2018), https://www.americanprogress.org/issues/lgbt/reports/2018/08/13/454592/protecting-basic-living-standards-lgbtq-people/; *see also* NAT'L HEALTH LAW PROGRAM, et al., MEDICAID AS AN LGBTQ REPRODUCTIVE JUSTICE ISSUE: A PRIMER, WHY MEDICAID IS AN LGBTQ ISSUE 2 (2019), https://healthlaw.org/resource/medicaid-as-an-lgbtq-reproductive-justice-issue-a-primer/ (citing Kerith J. Conron & Shoshana K. Goldberg, THE WILLIAMS INST., *LGBT Adults with Medicaid Insurance* 1 (2018), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Medicaid.pdf).

[52] Caitlin Rooney, Charlie Whittington & Laura E. Durso, CTR. FOR AM. PROGRESS, *Protecting Basic Living Standards for LGBTQ People* (Aug. 13, 2018), https://www.americanprogress.org/issues/lgbt/reports/2018/08/13/454592/protecting-basic-living-standards-lgbtq-people/.

While these are just a few examples of where LGBTQI discrimination would proliferate were the proposal to be codified, the effects will be felt across a wide range of HHS programs. For LGBTQI people, including LGBTQI people with disabilities, health disparities will be exacerbated. The Proposed Ruel cannot stand.

RECOMMENDATION: Retain all references to sexual orientation and gender identity across all HHS regulations.

V. LANGUAGE ACCESS

DREDF stands with our allies in opposing HHS' proposal to significantly weaken Section 1557's language access rights. Discrimination on the basis of language, just like discrimination on the basis of disability, creates unequal access to health care for the individuals and families who need accommodations from their health providers or insurers. Over twenty-five million Americans are limited English proficient ("LEP").[53] For LEP individuals, language assistance is critical to accessing and receiving health care and health insurance. The Proposed Rule, which would repeal Section 1557 regulations relating to meaningful language access, notice, tagline, and VRI requirements, threatens the civil rights of LEP persons.

A. Meaningful Access for LEP Individuals (45 C.F.R. § 92.201, Proposed § 92.101)

DREDF opposes the weakening of the regulatory language at 45 C.F.R. § 92.201 (redesignated § 92.101), concerning meaningful access for LEP individuals. We recommend retaining the current regulations for the following reasons.

First, proposed § 92.101 inappropriately changes the regulation's language from a requirement to provide meaningful access "to each individual with [LEP]" to a requirement to ensure meaningful access "to such program or activities by [LEP] individuals." This change shifts the focus of the regulation from an *individual's rights* to the covered entity's *programs or activities*, and it would thus weaken meaningful access and run contrary to the text of Section 1557. The proposed change would enable covered entities to establish generalized policies that may give insufficient attention to the specific, and sometimes unique and intersecting, needs of an LEP individual. For example, an LEP individual who also has a visual disability may require written materials in large font Spanish, rather than just the simple, Spanish language document. The proposed regulation could make this individual's dual needs more difficult to accommodate. In Section 1557, Congress declared that "an individual shall not" be subjected to discrimination. 42 U.S.C. § 18116. Section 1557 regulations cannot offer less protection than the statute that authorizes such regulations to be promulgated. The correct emphasis in the Section 1557 regulations must be on each individual and not on the programs.

Second, we oppose HHS' proposal to codify a four-factor test to determine an entity's compliance with Section 1557's meaningful access standards. In the 2016 Final Rule, HHS endorsed a two-factor test to determine compliance with the requirements, determining that this test was consistent with Title VI, the statute referenced in Section 1557 that prohibits national origin discrimination (which encompasses language discrimination). The protections in Section

[53] ASIAN & PACIFIC ISLANDER AM. HEALTH FORUM, Analysis of 2017 Am. Cmty. Survey ("ACS") Data.

1557 and its regulations cannot be anything less than those already guaranteed by Title VI. Incorporating the four-factor test now would negate the claims made by HHS in the current NPRM that it seeks to align Section 1557 with Title VI, as they are already in alignment. Additionally, in originally adopting the two-factor test that was based upon, informed by, and consistent with Title VI, HHS OCR was providing a method of articulating how it would engage in enforcement review in the health care context—a specific application of Title VI and newly created by Section 1557. The two-factor test correctly incorporates the principles in HHS' LEP Guidance and it allows HHS OCR to better explain how the factors will be considered in their application to health programs and activities under Section 1557, while also giving substantial weight to the nature and importance of the particular communication at issue.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.201 in its entirety.

B. Video Remote Interpreting Standards (45 C.F.R. § 92.201(f), Proposed § 92.101(b)(3)(iii))

Additionally, while DREDF appreciates that HHS proposes to incorporate the ADA's definition of video remote interpreting ("VRI") services[54] for the purposes of effective communication for people with disabilities, we oppose the removal of the technical and training requirements for the use of VRI for spoken language interpretation. *See* 84 Fed. Reg. at 27866, 27887.

VRI can provide a necessary additional tool for accommodating LEP individuals in the health care setting. Depending on the nature of the communication with a health care provider or health insurer, VRI may be more appropriate than telephonic interpretation. For example, while the telephone may be appropriate for scheduling a medical appoint, it is not appropriate for interpreting information related to trauma, mental health, or death. Non-verbal cues are critically important in many health care contexts, such as when a provider writes and explains a new prescription, and they simply cannot be observed via telephone.

VRI is also cost-efficient. While there are higher costs in equipment and training, VRI has saved costs in relation to in-person interpreting, as there are no minimums, travel time, or cancellation risks. While we maintain that in-person interpreting is still best option for the patient, VRI can be an appropriate, cost-saving alternative in some contexts. Keeping the current standards will allow the health care provider and the patient to jointly determine which technology is appropriate in a given situation, and when an entity uses those VRI services, ensure that it is a high quality video with a reliable connection.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.201(f) in its entirety.

[54] *See* 28 C.F.R. §§ 35.104, 36.303(f).

C. Taglines (45 C.F.R. § 92.8)

DREDF opposes the proposed elimination of the Section 1557 regulations requiring taglines in notices in the top fifteen languages spoken by LEP individuals in the state. DREDF strongly objects to the proposed removal of the general notice requirements at 45 C.F.R. § 92.8, as explained in further detail *infra* Section VI.C. We are also concerned, for purposes of language equity, at the accompanying elimination of the tagline requirement.

The inclusion of taglines is essential for effectuating the civil rights of LEP persons. Taglines are a cost-effective approach to ensure that covered entities provide language access while not being overly burdened. In the absence of translated documents, taglines are necessary "to ensure that individuals are aware of their protections under the law, and are grounded in OCR's experience that failures of communication based on the absence of auxiliary aids and services and language assistance services raise particularly significant compliance concerns under Section 1557, as well as Section 504 and Title VI." 2015 Proposed Rule, 81 Fed. Reg. at 54193.

Taglines are also well-supported by existing federal and state regulations, guidance, and practice.[55] Moreover, in proposing to change this long-standing requirement, HHS has provided an insufficient regulatory impact analysis, which fails to identify and quantify costs to protected individuals. It has provided no tangible analysis on the costs and burdens to protect individuals from the removal of the notice and tagline requirements. The costs are not only reduced awareness of language services by LEP persons, but also reduced awareness by the general public about their rights as protected by Section 1557. The current regulations should be maintained.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.8 in its entirety.

[55] *See* 29 C.F.R. § 42.405(d)(1) (Title VI Coordination Regulations); 45 C.F.R. § 155.205(c)(2)(iii) (Marketplace and QHP Issuer Requirements); 42 C.F.R. § 438.10(d)(3) (Medicaid Managed Care Plans); 29 C.F.R. § 38.9(g)(3) (DOL WIOA Nondiscrimination Requirements); 7 C.F.R. § 272.4(b) (USDA SNAP Bilingual Requirements); 2003 HHS LEP Guidance.

VI. IMPLEMENTATION AND ENFORCEMENT MECHANISMS

DREDF also opposes HHS' proposal to eliminate several regulations that are integral to implementing and enforcing the Section 1557's prohibition on discrimination against people with disabilities, including the regulations relating to definitions (45 C.F.R. § 92.4); the designation of a responsible employee and adoption of grievance procedures (§ 92.7); notice requirements (§ 92.8); and private right of action and compensatory damages (§ 92.301).

A. Definitions (45 C.F.R. § 92.4)

DREDF strongly opposes the deletion of 45 C.F.R. § 92.4, an essential provision that contains definitions for the Section 1557 regulations. This deletion will serve to create confusion among covered entities and inconsistency of terms among the many regulations that currently reference or otherwise rely on the underlying definitions in § 92.4.

Moreover, as an organization dedicated to enforcing the rights of people with disabilities, we are specifically concerned with HHS deletion of disability-related definitions. HHS contends that the "proposed rule retains most of the disability-rights related definitions from the current rule either explicitly . . . ; by using the definition to describing the requirements or characteristics of the entity; or by referencing underlying regulations or statutes, such as for technical accessibility standards and definitions." 84 Fed. Reg. at 27860. However, as explained in Section III.A above, the text of the Proposed Rule demonstrates that HHS has altered crucial definitions related to effective communication, without any explanation or even acknowledgement that it is doing so. We urge HHS to retain all current definitions in § 92.4

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.4 and the full definitions articulated therein.

B. Grievance Procedures and Responsible Employee (45 C.F.R. § 92.7)

DREDF opposes the elimination of the Section 1557 regulatory requirements related to the designation of a responsible employee and adoption of grievance procedures, as currently codified at 45 C.F.R. § 92.7. These requirements are critical for holding covered entities responsible for the protections provided by Section 1557. Without a designated employee and defined grievance procedure, many individuals protected by Section 1557 may not receive the information they need to avoid discrimination, identify when their rights have been violated, or seek redress for discrimination faced. Across a range of covered entities, DREDF has seen how employees can "pass the buck" when it comes to meeting requests from patients with disabilities for reasonable accommodation and policy modifications. Similarly, complaints about the failure to received needed accommodations and policy modifications can easily be ignored unless entities have clearly designated grievance procedures and assigned responsibility for disability nondiscrimination to a particular employee.

Other federal civil rights laws require designation of a responsible employee and creation of grievance procedures; retaining the regulatory grievance procedure for Section 1557 should not create a significant or even a new burden on covered entities. HHS could also determine that processes in place to support Section 1557 are evidence of compliance with other pre-existing requirements. This regulation should be retained.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.7 in its entirety.

C. Notice Requirements (45 C.F.R. § 92.8)

DREDF strongly supports the notice and tagline requirements currently contained at 45 C.F.R. § 92.8, which ensure that covered entities inform beneficiaries, enrollees, applicants, and members of the public of the availability of language services and auxiliary aids and services, and that the entity does not discriminate on the basis of race, color, national origin, sex, age or disability. The Proposed Rule, which seeks to eliminate this regulation in its entirety, is inconsistent with Section 1557 and should not be finalized.

Title 45 C.F.R. § 92.8 requires covered entities to provide notice of the following:

(1) The covered entity does not discriminate on the basis covered by Section 1557;
(2) The covered entity provides auxiliary aids and services for people with disabilities;
(3) The covered entity provides language assistance services for individuals with LEP;
(4) How to obtain auxiliary aids and services;
(5) How to obtain language services;
(6) The availability of the grievance procedure; and
(7) How to file a discrimination complaint with HHS OCR.

Section 1557's notice regulation is integral to ensuring that health care consumers are informed of their rights and the availability of needed accommodation services and complaint mechanisms. Elimination of this regulation is unjustified and would be wholly inconsistent with the text and intent of the ACA.

First, the proposed elimination of the notice requirement compromises and diminishes the primacy of the nondiscrimination message of Section 1557. To clearly communicate a covered entity's nondiscrimination obligations and an individual's right to access services, a notice must be posted in physical locations, on websites, and sent with significant documents, as the current regulations provide. If an individual enters an emergency department, for example, he or she needs to know immediately how to obtain auxiliary aids and services; otherwise, his or her medical care, health, and even life may be compromised. Similarly, if an individual cannot communicate with their insurance provider to obtain information on how to access covered services or benefits, they may suffer serious harm and be forced to forgo necessary care.

Eliminating the notice requirement will cause many individuals to not know of their rights or how to obtain necessary services. As HHS itself noted, "repealing the notice of nondiscrimination requirement may result in additional societal costs, such as decreased utilization of auxiliary aids and services by individuals with disabilities." 84 Fed. Reg. at 27883. Any burdens of wall space and use of information technology, staff, and resources to post the notice and include it on a website are greatly outweighed by the benefits of having the notice visible and conspicuous such that individuals may access the services promised by Section 1557 and as outlined in the notice.

Second, the notice requirements of Section 1557 are not duplicative of any other requirements, including those of Section 504 or Title VI. The notice requirements in the current regulations are explicit and designed to adequately inform individuals of the scope of their rights under Section 1557. Additionally, Section 1557 applies to a broader array of covered entities than the civil rights laws on which it builds. It applies specifically to federally-administered health programs and activities, as well as entities created under Title I of the ACA. By eliminating the notice requirements, HHS has effectively exempted a large swath of covered entities from informing individuals of their civil rights.

Third, while we recognize that some covered entities have raised concerns about how often they have to send the Section 1557 notice with significant documents, this burden does not justify the wholesale elimination of the requirement. Rather, HHS could consider a variety of other options, including an explanation of what constitutes significant documents or how often a covered entity has to send a notice if the covered entity sends multiple significant documents to individuals over the course of a year. Indeed, in comments submitted by health insurers and medical associations in response to the 2015 Proposed Rule, the overriding question was about the frequency of sending notices or taglines rather than the need to send them at all.

Finally, HHS fails to provide adequate evidence for its purported cost-saving justifications. HHS fails to calculate the specific costs related to posting notices, focusing almost entirely on the cost associated with mailings. Its analysis also does not separate out the costs for providing notices of nondiscrimination versus the costs related to including taglines in other languages, thereby making it impossible to appropriately understand which costs are related to providing these notices in English and which costs are related to taglines. Further, HHS fails to explain why completely eliminating the notice requirements is justified given the prior analysis it undertook in adopting these requirements just a few short years ago. By not fully explaining why the elimination of this important requirement is necessary, HHS fails to justify its proposal. We oppose the repeal of requirements related to notices.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.8 in its entirety.

D. Enforcement Mechanisms (45 C.F.R. § 92.301, Proposed § 92.5)

DREDF further objects to HHS' proposal to eliminate 45 C.F.R. § 92.301 ("Enforcement Mechanisms") and replace it with proposed § 92.5, as the latter incorrectly interprets the standard of discrimination under Section 1557 and it erroneously fails to recognize a private right of action for compensatory damages.

In the Proposed Rule, HHS incorrectly attempts to limit the remedies available under Section 1557. Congress intentionally designed Section 1557 to build upon and expand prior civil rights laws such that individuals seeking to enforce their rights would have access to the full range of available civil rights remedies and not be limited to only the remedies provided to a particular protected group under prior civil rights laws. Section 1557 expressly provides individuals access to any and all of the "rights, remedies, procedures, or legal standards available" under the cited civil rights statutes, regardless of the type of discrimination. Rather than recognizing that the statute creates a single standard for addressing health care discrimination, HHS' reinterpretation of the statute in this proposal would instead attempt to create multiple, piecemeal legal standards and burdens of proof derived from different statutory contexts. This interpretation is contrary to Section 1557's statutory language and Congress' intent.

The proposed language is not a valid interpretation of Section 1557. While the statute expressly sets out the grounds of discrimination by reference to pre-existing civil rights statutes, it does not incorporate separate and distinct remedies, legal standards, and burdens of proof for each of the prohibited bases of discrimination.[56] To the contrary, Congress specified that "[t]he enforcement mechanisms provided for and available under such title VI, title IX, section 504, *or* such Age Discrimination Act shall apply for purposes of violations of this subsection." 42 U.S.C. § 18116(a) (emphasis added). The use of the disjunctive "or" indicates that *any* of the enforcement mechanisms applicable under any of the incorporated statutes are available to every claim of discrimination under Section 1557, regardless of the particular protected class triggering the claim. Applying standard rules of construction, all of the enforcement mechanisms provided for and available under each of the generally incorporated statutes in Section 1557 are available to every claim of discrimination under Section 1557.

It is also necessary to read Section 1557 as establishing a single standard for health care discrimination in order to avoid "patently absurd consequences."[57] HHS' proposal "would lead to an illogical result, as different enforcement mechanisms and standards would apply to a Section

[56] *See, e.g.*, Sarah G. Steege, *Finding A Cure in the Courts: A Private Right of Action for Disparate Impact in Health Care*, 16 MICH. J. RACE & L. 439, 462 (2011) ("[T]here is no indication in § 1557 that each listed statute's enforcement mechanisms apply only to its own protected classes."); *Rumble*, 2015 WL 1197415, at *10–11.
[57] *See* United States v. Brown, 333 U.S. 18, 27 (1948).

1557 plaintiff depending on whether the plaintiff's claim is based on her race, sex, age, or disability."[58] Moreover, courts would be left without guidance on how to address intersectional claims: should a person who alleges discrimination on the basis of both race and age be subject to the standards and enforcement mechanisms under a title IX analysis or the ADEA? Congress explicitly adopted one provision to prohibit all discrimination in health care. It strains imagination to read that one provision to require agencies and courts to apply a hodgepodge of different standards and enforcement mechanisms.

Further, the proposed changes do not comport with congressional intent. Congress did not intend the enforcement mechanisms and standards available under Section 1557 to be tethered to the nature of the claim. Rather, in enacting Section 1557, Congress sought to "create a new right and remedy in a new context without altering existing laws."[59] Congress has repeatedly expressed that it intends civil rights laws to be broadly interpreted in order to effectuate their remedial purposes.[60] By trying to narrowly limit the legal standards and burdens of proof that apply to those who have experienced health care discrimination, HHS' interpretation of Section 1557 would ignore Congress' intent to provide broad remedies to address discrimination.

Some courts have interpreted Section 1557 to apply different enforcement mechanisms and standards depending on the individual's protected class, citing Section 1557's reference to the enforcement mechanisms of the four cited civil rights statutes.[61] However, the courts in these cases miscomprehend the statutory language, its context, and U.S. Supreme Court case precedent. The Supreme Court has already held that a statute's incorporation of another statute's enforcement mechanisms does not necessarily incorporate its standards of actionable discrimination.[62] Moreover, as previously discussed, Section 1557 expressly provides for broad and uniform enforcement that is consistent with Congress' intent that civil rights laws provide broad remedies. While Congress could perhaps have more clearly articulated its intent to establish a single statutory standard for determining discrimination and enforcing Section 1557, its failure to perfectly articulate such a standard does not necessitate the narrow reading of the

---

[58] *See Rumble*, 2015 WL 1197415, at *11.
[59] *Id.* at *11, n.6.
[60] *See, e.g.*, Kang v. U. Lim Am., Inc., 296 F.3d 810, 816 (9th Cir. 2002); *see also* H.R. REP. NO. 102–40, pt. 1, at 88 (1991), *reprinted in* 1991 U.S.C.C.A.N. 549, 626 (stating that "remedial statutes, such as civil rights law[s], are to be broadly construed").
[61] *See, e.g.,* SEPTA v. Gilead, 102 F. Supp. 3d 688, 699 n.3 (E.D. Pa. 2015); Briscoe v. Health Care Serv. Corp., 281 F. Supp. 3d 725, 738 (N.D. Ill. 2017); *see also, e.g.,* Doe v. BlueCross BlueShield of Tenn., Inc., 926 F.3d 235, 241 (6th Cir. 2019).
[62] *See* CONRAIL v. Darrone, 465 U.S. 624 (1984) (holding that Section 504's incorporation of the "remedies, procedures, and rights" set forth in Title VI did not mean that Section 504 incorporated Title VI's substantive limitations on actionable discrimination).

statute articulated in the NPRM and the cases it cites.[63] These cases overly rely on interpretations of the underlying statutes without recognizing the inherent shifts that the ACA made in the health care realm.[64] If Section 1557 were limited by the constraints of the referenced statutes, its passage would have been largely unnecessary, as the four civil rights statutes already apply to organizations "in the business of providing . . . health care."[65]

Finally, we also oppose HHS' proposed elimination of § 92.301(b), concerning Section 1557's private right of action for compensatory damages. Every court that has ruled on the question has found that the statutory language of Section 1557 confers a private right of action. The existence of such a right is clear from Section 1557's statutory language, which explicitly references the "enforcement mechanisms" of the four civil rights laws listed—*all of which* contain a private right of action. Once again, this understanding is also consistent with Congress' intent for civil rights laws to be broadly interpreted to effectuate their remedial purposes. Removing the regulatory language that confirms Section 1557's private right of action and available damages will serve only to confuse. HHS should not finalize this proposal.

RECOMMENDATION: HHS should retain 45 C.F.R. § 92.301 in its entirety.

---

[63] *See* King v. Burwell, 135 S. Ct. 2480, 2492 (2015) (noting that the ACA "contains more than a few examples of inartful drafting" and thus emphasizing the importance of considering the broader context of the statute).

[64] The Supreme Court has recognized that the ACA's broad purpose is to "expand insurance coverage . . . [and] ensure that anyone can buy insurance." *Id.* at 2493. An expansive prohibition on health care discrimination is key to ensuring that *anyone* can buy insurance. Thus, other courts have properly concluded that a single standard and burden of proof apply to Section 1557: "looking at Section 1557 and the [ACA] as a whole, it appears that Congress intended to create a new, health-specific, anti-discrimination cause of action that is subject to a singular standard, regardless of a plaintiff's protected class status." *Rumble*, 2015 WL 1197415, at *10.

[65] *See, e.g.*, 29 U.S.C. § 794 (Section 504 of the Rehabilitation Act).

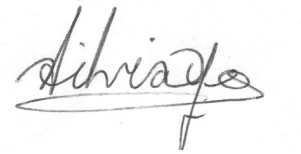
VII. CONCLUSION

People with disabilities, like all people, have intersectional identities. The anti-discrimination mandate in Section 1557 is designed to prohibit discrimination based on a single identity as well as the intersection of two or more identities, such as race and disability, age and disability, or sex and disability. We therefore strongly oppose the proposed changes to the Section 1557 regulations, which seek to eliminate and limit protections for LEP individuals, LGBTQI persons, women, *and* persons with disabilities and chronic conditions. Section 1557 addresses not only protections for each protected class covered, but the intersection of those protections. As such, this proposal's attack on the civil rights of one group is an attack on the civil rights of all. We stand in solidarity with other marginalized groups in objecting to these proposed changes.

We strongly recommend that HHS not finalize any part of the Section 1557 Proposed Rule or the other conforming provisions. HHS should instead leave the current Section 1557 regulations, as codified by the 2016 Final Rule, in place in their entirety.

Thank you again for the opportunity to comment on the proposed rule. Please do not hesitate to contact us if you have any questions about the above.

Sincerely,



Carly A. Myers
Staff Attorney

Silvia Yee
Senior Staff Attorney

DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice

August 13, 2019

Roger Severino
Director, Office for Civil Rights
U.S. Department of Health and Human Services
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

RE: HHS Docket No. HHS-OCR-2019-0007, RIN 0945-AA11, Comments in Response to Section 1557 NPRM

Dear Mr. Severino,

Disability Rights North Carolina (DRNC) is the designated Protection & Advocacy (P&A) organization in North Carolina, mandated to advance the rights of people with all types of disabilities, of all ages, statewide. Through our work providing information, outreach, training, advocacy and legal representation to our diverse constituency on a broad array of substantive issues, our team has developed significant, specialized experience and expertise regarding the challenges disabled North Carolinians struggle to overcome on a daily basis. Among these challenges are access to quality health and mental health care services, community-based long-term care, medical equipment and assistive technology.

DRNC appreciates this opportunity to share our views on the proposed policy changes in interpreting and enforcing the nondiscrimination provision of the Affordable Care Act (ACA) referenced above, and writes to express our opposition to the U.S. Department of Health and Human Services (HHS) proposed rule on Section 1557. The proposed rule would cause major harm to people with disabilities and their families and communities; it's unfair, discriminatory and bad policy for this country. HHS should not revise these regulations or act to limit the applicability of Section 1557. DRNC strongly recommends that HHS not finalize this regulation in whole or in part.

Section 1557 and its implementing rules are critical for the people we serve. Disabled people are routinely discriminated against in health programs and activities. From mass segregation to forced sterilization, inaccessible health care services to flat out denial of services, health care and insurance providers too often deprive people with disabilities the right to live in the world. For the disability community, receiving appropriate, accessible care and nondiscriminatory health insurance is a foundational first step to living independent and productive lives.

North Carolina's Protection and Advocacy System
3724 National Drive
Suite 100
Raleigh, NC 27612
919-856-2195
877-235-4210
888-268-5535 TTY
919-856-2244 fax
www.disabilityrightsnc.org

DRNC appreciates that HHS seeks to reduce costs. Yet the proposed rule devalues the civil rights of health care consumers, particularly individuals and families who already face pervasive physical, programmatic, and attitudinal barriers in the health care context. The proposed changes to the Section 1557 regulations would significantly diminish the access rights of already disadvantaged groups and have a disproportionately harmful effect on health outcomes for people with disabilities.

Context is important. HHS underwent an extensive process to develop regulations for Section 1557, including a Request for Information, proposed rule, and final rule. HHS considered more than 24,875 public comments submitted for the 2016 rule. There is no compelling public policy basis to reopen this rule and ignore the reasoned process HHS has already undertaken.

It is vital that HHS retain the current definition of a "covered entity." The proposed rule seeks to radically narrow the scope and applicability of Section 1557, contrary to the plain meaning of the statute. Congress made clear in Section 1557 that if one part of an entity receives federal financial assistance, the entire entity should be covered; further, it wisely intended that Section 1557 address discrimination in health insurance. By way of example, in North Carolina, we receive reports of private health insurance denying therapy for children with autism and, prior to the ACA, insurance plans routinely disadvantaged people with disabilities by requiring them to pay unaffordable fees and co-pays for necessary healthcare. Allowing discrimination to go unchecked costs people with disabilities and taxpayers alike by increasing the need for government assistance. Congress intended to eliminate these collateral costs caused by private health insurance discrimination.

We disagree with HHS' proposal to delete the current requirement that covered entities provide notice, with every significant communication to individuals, that they do not discriminate based on disability or other prohibited grounds; that they provide auxiliary aids and services for people with disabilities, including qualified interpreters and information in alternate formats; and how to obtain those auxiliary aids and services. Without the notice, members of the public will have limited means of knowing that auxiliary aids and services are available, how to request them, what to do if they face discrimination, and their right to file a complaint. As HHS itself notes in the proposed rule, "repealing the notice of nondiscrimination requirement may result in additional societal costs, such as decreased utilization of auxiliary aids and services by individuals with disabilities due to their reduced awareness of such services." We agree and understand this issue all too well. Removing the notice requirement will further perpetuate discrimination. In North Carolina, even our largest health care system does not understand its obligations to provide materials in Braille or large print, nor do many of our medical providers. Further, removing requirements for Video Remote Interpreting would be extremely detrimental to Deaf and Hard of Hearing people. The benefit of requiring health programs to provide notices of auxiliary aids and services has the dual benefit of both informing patients of their rights to auxiliary aids or services and clarifying to health programs their responsibilities under the law. Removing the notice requirement leads to greater confusion and increased litigation, and we must object to removing it.

We urge HHS to retain the language in the 2016 Final Rule regarding effective communication for individuals with disabilities. In the proposed rule, HHS changes the definition of auxiliary aids and services, and does so without explanation. HHS claims to

import the definition of auxiliary aids and services from the regulations for Title II of the Americans with Disabilities Act, but deletes "[a]cquisition or modification of equipment and devices; and [o]ther similar services and actions" from the list of examples of aids and services. This could create confusion, as it takes what is now a clearly illustrative list and implies that it is exhaustive. HHS should retain the definition of "auxiliary aids and services" from the 2016 final rule. Furthermore, we oppose any proposal to exempt entities with 15 or fewer employees from the requirement to provide effective communication. Effective communication is a basic prerequisite of quality health care services. Patients need to communicate with their doctors, understand medical instructions, and pay costly medical bills in a timely manner. In some areas of the country, this exemption could effectively bar access to many providers, including specialists who are essential to providing high quality health care to individuals with chronic health conditions.

HHS should retain strong, clear language prohibiting insurance companies from discriminating on the basis of race, color, national origin, sex, age, or disability in a number of areas, including marketing plans, designing benefits, coverage claims, or imposing additional costs. These protections are especially important for people with disabilities and those with serious or chronic conditions. Eliminating this regulatory provision could result in health insurers illegally excluding important benefits, designing their prescription drug formularies in a way that limits access to medically necessary care, or cherry-picking healthier enrollees through marketing practices. It may make it harder for people who experience discrimination to enforce their rights through administrative and judicial complaints.

We oppose HHS' proposal to delete regulations that prohibit discrimination on the basis of association with a protected class. This will create uncertainty and confusion regarding the responsibilities of providers and the rights of persons who experience discrimination, and inconsistencies with other regulatory requirements that entities are subject to, including the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.

We also believe that HHS incorrectly limits the remedies available under Section 1557 in the proposed changes to § 92.301 (newly designated § 92.5). One of the goals of Section 1557 was to build and expand on prior civil rights laws such that individuals seeking to enforce their rights would have access to the full range of available civil rights remedies and not be limited to only the remedies provided to a particular protected group under prior civil rights laws. This is why Section 1557 expressly provides individuals access to any and all of the "enforcement mechanisms provided for and available under" the cited civil rights statutes, regardless of the type of discrimination. The proposed rule makes it harder and more complicated to address prohibited discrimination, at the expense of basic accountability. HHS should retain current § 92.301.

HHS should not change the current requirements to provide "reasonable modification," and import exemptions for "undue hardship." The substitute language is from regulations related to employment, and is unnecessary, ill-fitting, and inappropriate for a health care context. Exemptions should not exist regarding elevators in multistory buildings, as this is likely to severely limit access to necessary medical care. We also note that people with disabilities, like all people, have intersectional identities, and the anti-discrimination mandate in 1557 is designed to prohibit discrimination based on a single identity as well as the intersection of two or more identities such as race and disability, age and disability, or sex and disability. The proposed rule seeks to strip protections from persons with limited English proficiency,

LGBTQ individuals, and women. We stand in solidarity with other marginalized groups in objecting to this proposed rule. It would seriously impede our efforts in North Carolina to facilitate the entry of multiply marginalized individuals into the economic mainstream.

Thank you for the opportunity to provide comments on the proposed rule and considering our views. In summary, we urge HHS not to finalize these changes. If you have questions about our comments, please contact me: Virginia.KnowltonMarcus@DisabilityRightsNC.org or 916-856-2195.

Sincerely,

Virginia Knowlton Marcus
Chief Executive Officer
Disability Rights North Carolina

FUNDERS FOR LGBTQ ISSUES

July 25, 2019

Submitted via www.regulations.gov

Secretary Alex Azar
Department of Health and Human Services, Office for Civil Rights
Attention: Section 1557 NPRM, RIN 0945-AA11
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

RE: Comments in Opposition to Section 1557 NPRM, RIN 0945-AA11, "Nondiscrimination in Health and Health Education Programs or Activities"

To Whom It May Concern:

I am writing on behalf of Funders for LGBTQ Issues to express our strong opposition to the proposed regulatory reform regarding Section 1557 of the Patient Protection and Affordable Care Act published in the Federal Register on June 14, 2019.

Funders for LGBTQ Issues works to increase the scale and impact of philanthropic resources aimed at enhancing the well-being of lesbian, gay, bisexual, transgender and queer communities, promoting equity, and advancing racial, economic and gender justice. We are a network of more than 80 foundations, corporations, and other grantmaking institutions that collectively award more than $1 billion in funding annually, including more than $100 million specifically devoted to LGBTQ issues.

With an awareness that LGBT Americans are 25 percent more likely to lack healthcare coverage compared to non-LGBT Americans, our network is actively working to address health disparities affecting LGBT Americans.[1] We know that LGBT Americans suffer from higher rates of cancer, cardiovascular disease, HIV/AIDS infection, and mental health issues.[2] Our most recent tracking report on LGBTQ grantmaking by U.S. foundations identified $27.6 million in funding aimed at improving the health and wellbeing of the more than 11.3 million Americans who openly identify as lesbian, gay, bisexual, or transgender.[3,4] Legislation or rules that reduce

[1] The Williams Institute, UCLA School of Law, "LGBT Data & Demographics," accessed July 16, 2019. https://williamsinstitute.law.ucla.edu/visualization/lgbt-stats/?topic=LGBT#demographic

[2] Brown, J., Maulbeck, B.F, (2015) *Vital Funding: Investing in LGBTQ Health and Wellbeing*. Retrieved from Funders for LGBTQ Issues Website: https://lgbtfunders.org/wp-content/uploads/2018/04/Vital_Funding.pdf

[3] Kan, L.M., Maulbeck, B.F., Wallace, A. (2018) *2017 Tracking Report: Lesbian, Gay, Bisexual, Transgender, and Queer Grantmaking by U.S. Foundations*. Retrieved from Funders for LGBTQ Issues Website: https://lgbtfunders.org/wp-content/uploads/2018/02/2017TrackingReport_Final.pdf

protections or limit health care access for LGBT Americans run counter the goals of our network and jeopardize the health of millions of people already facing alarming health crises.

As such, we oppose the proposed rules change, which will inflict unnecessary harm on LGBT Americans -- in particular, more than one million transgender Americans.[5] The proposal to remove the protections of Section 1557 is counter to long-standing federal court decisions from across the country that classified discrimination on the basis of sexual orientation and gender identity as sex discrimination. Nearly seven million LGBT Americans live in states without any protections against sexual orientation and gender identity discrimination in public accommodation.[6] Section 1557 was wisely added to clarify existing law that discrimination against LGBT persons in healthcare settings and in insurance benefits coverage is unlawful; the proposed rule change would sow confusion among healthcare workers and insurance companies and give the impression that such discrimination is permissible. Given that one in three transgender Americans report having had at least one negative experience with a healthcare provider, such as verbal harassment or refusal of treatment entirely, the proposed regulations would only further discourage more than one million transgender Americans from seeking medical care.[7]

Furthermore, the broad religious exemptions proposed in the change threaten to turn personal and religious beliefs into a smokescreen for discrimination. They could be used not only to deny care to LGBT individuals but also to prevent people from accessing needed reproductive healthcare, letting doctors decide who is "worthy" of treatment. Allowing medical providers to use their personal beliefs rather than their professional obligations to decide whom they will serve could result in a wide range of people being turned away from potentially life-saving care: LGBT people, unmarried people, or people who have had an abortion or need one. The result would be a "patchwork" of unequal access to reproductive healthcare across the country, where the nature and quality of care available would be based on the happenstance of geography rather than need.

---

[4] The Williams Institute, UCLA School of Law. (2019) *Adult LGBT Population in the United States*. Retrieved from Williams Institute Website https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Population-Estimates-March-2019.pdf

[5] The Williams Institute, UCLA School of Law. (2019) *Adult LGBT Population in the United States*. Retrieved from Williams Institute Website: https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Population-Estimates-March-2019.pdf

[6] The Williams Institute, UCLA School of Law (2019) *LGBT People in the U.S. Not Protected by State Nondiscrimination Statutes*. Retrieved from Williams Institute Website: https://williamsinstitute.law.ucla.edu/wp-content/uploads/Equality-Act-April-2019.pdf

[7] James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016) *The Report of the 2015 U.S. Transgender Survey*. Retrieved from National Center for Transgender Equality Website: https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf

We also oppose the proposed rules change because of negative impact it will have on the health outcomes of immigrants -- nearly one million of whom identify as lesbian, gay, bisexual, or transgender.[8] By eliminating not only vital anti-discrimination protections but also the requirement that health programs post notices about the availability of language access programs, the proposed change to Section 1557 makes it harder for people with limited English proficiency or other disabilities to access medical care. Without meaningful access to information about their rights to care, patients and their family members with limited English proficiency would be less able to file complaints with HHS or in courts if their rights are violated. Moreover, as the current administration has shown outright hostility to immigrants, eliminating Section 1557's specific mandate that discrimination based on immigration status is prohibited may discourage immigrants from seeking healthcare altogether, for fear that doing so would also subject them to increased scrutiny about their immigration status. Any segment of the population that is forced to forgo treatment poses a threat to the health of the entire population.

For all the aforementioned reasons, we believe the proposed change to Section 1557 of the Patient Protection and Affordable Care is not only a step backwards but also highly inconsistent with the original intent of the law to expand access to healthcare and insurance. We hope you will reconsider the proposed change to Section of 1557 in the service of securing a healthier future for all Americans.

We thank you for your consideration.

Sincerely,

Ben Francisco Maulbeck
President
Funders for LGBTQ Issues

[8] Machado, D. Maulbeck, B.F. (2014) *Pathways Forward: Foundation Funding for LGBTQ Immigration Issues*. Retrieved from Funders for LGBTQ Issues Website: https://lgbtfunders.org/wp-content/uploads/2018/04/Pathways_Forward_2014.pdf

the Williams INSTITUTE

LGBT Data & Demographics
Switch Topic

ALL
Select a State

ALL
Select a Characteristic

United States

Male 42% Female 58%
LGBT Gender Ratio

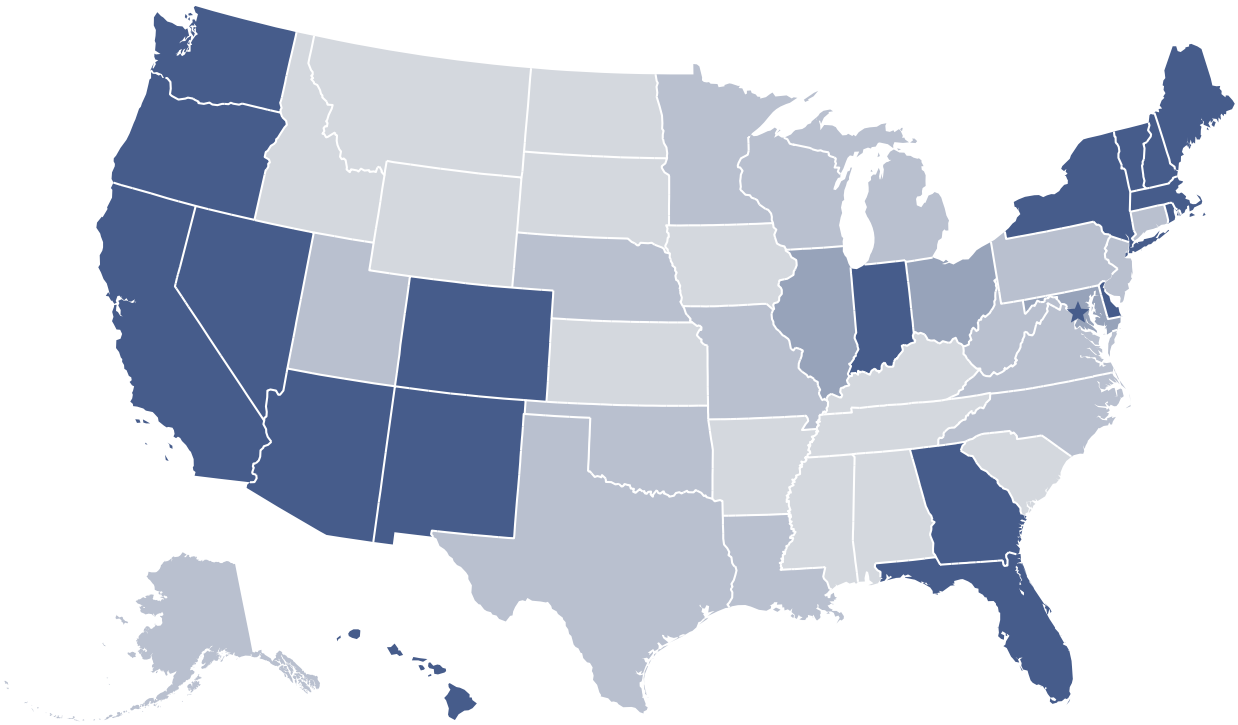
25%
Percentage with Income <$24K

4.5%
LGBT percentage of population

29%
Percentage with Children

AREA SELECTION

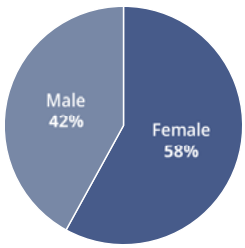
4.5% and above



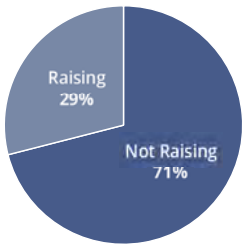
WHO IS INCLUDED IN THE LGBT ESTIMATES?

The Gallup Daily tracking survey asks respondents, "Do you, personally, identify as lesbian, gay, bisexual, or transgender?". We include all individuals in the data that self-identified as LGBT (both single and coupled). That is who is presented on these maps and charts. Thus, these data give a peek at the characteristics of the LGBT community living in the United States as a whole.

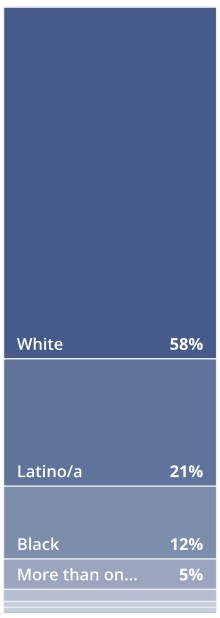
Characteristics of LGBT People: United States



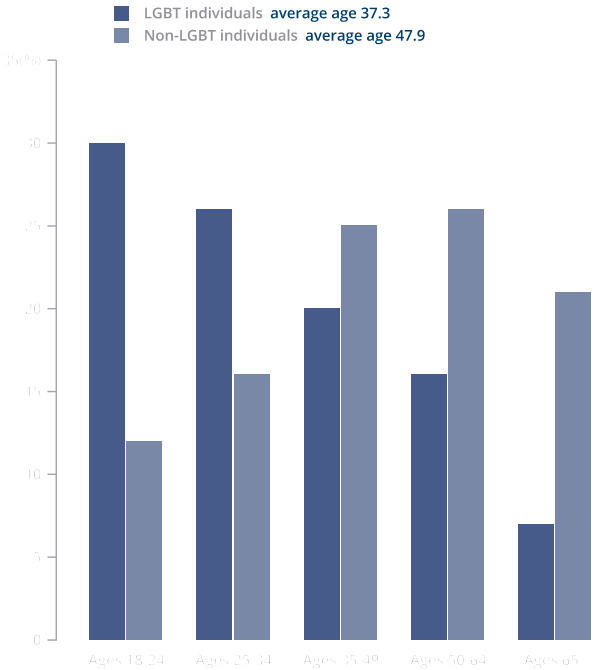
GENDER



% RAISING CHILDREN

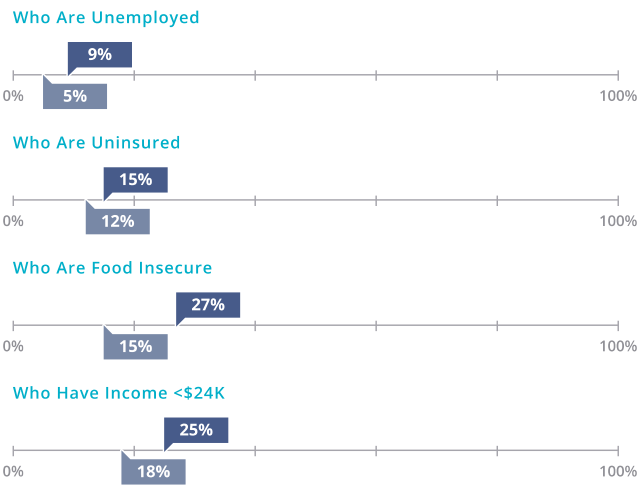


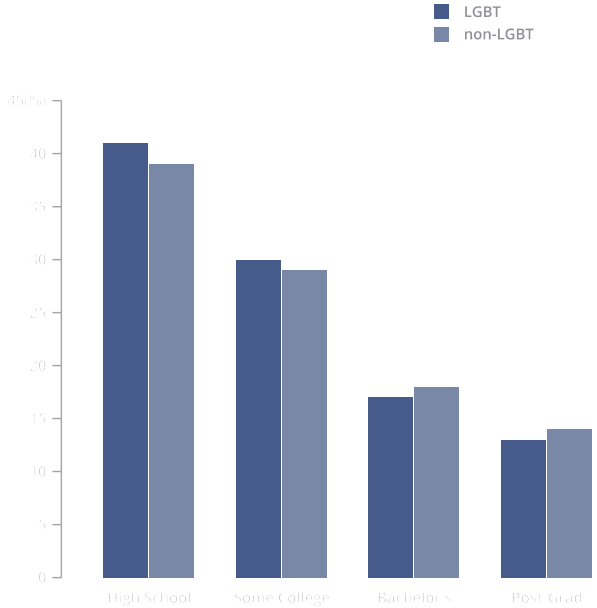
RACE/ETHNICITY



AGE DISTRIBUTION

Socioeconomic Indicators: United States





EDUCATIONAL ATTAINMENT

LGBT People Rankings: United States

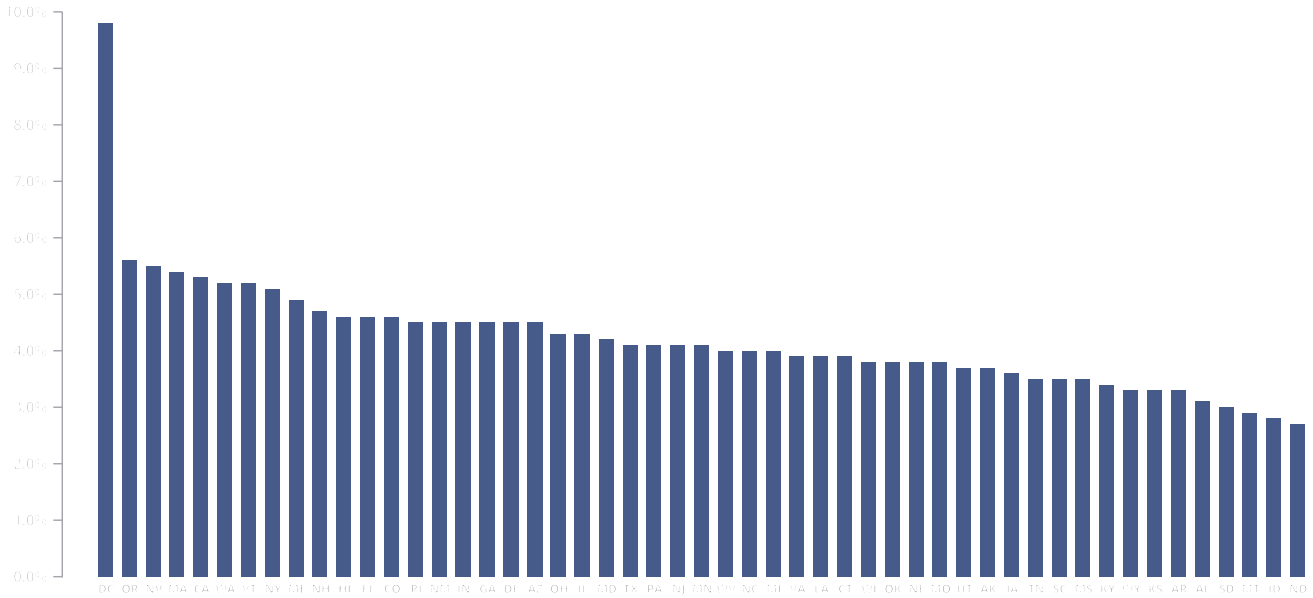
RANK	STATE	% OF LGBT INDIVIDUALS WITH CHILDREN	LGBT PERCENTAGE
1	District Of Columbia	9%	9.8%
2	Oregon	23%	5.6%
3	Nevada	22%	5.5%
4	Massachusetts	21%	5.4%
5	California	24%	5.3%
6	Washington	28%	5.2%
7	Vermont	23%	5.2%
8	New York	22%	5.1%

RANK	STATE	% OF LGBT INDIVIDUALS WITH CHILDREN	LGBT PERCENTAGE
9	Maine	21%	4.9%
10	New Hampshire	31%	4.7%
11	Hawaii	30%	4.6%
12	Florida	24%	4.6%
13	Colorado	25%	4.6%
14	Rhode Island	19%	4.5%
15	New Mexico	29%	4.5%
16	Indiana	34%	4.5%
17	Georgia	27%	4.5%
18	Delaware	35%	4.5%
19	Arizona	25%	4.5%
20	Ohio	30%	4.3%

State Comparison: All LGBT Individuals

LGBT PERCENTAGE OF POPULATION

Select a Statistic to Compare



About the Data

ABOUT THE DATA

Analysis in this interactive utilize data collected for the Gallup Daily Tracking survey. Respondents were obtained through list-assisted random digit dial (70% cell phone, 30% landline) and randomly assigned to one of two surveys within the Daily Tracking survey—the Gallup-Sharecare Well-Being Index or the Gallup Politics and Economy survey. Both surveys are interviewer-administered by telephone, may be completed in English or Spanish, and contain some of the same questions. Each year between 2012 and 2016, a sample of approximately 350,000 U.S. adults ages 18 and up who reside in the 50 states and the District of Columbia participated in the surveys. In 2017, Politics and Economy survey respondents were recruited daily, and those assigned to the Well-Being Index were recruited daily for the first half of 2017, then weekly starting in July 2017, resulting in a slightly smaller sample for 2017 (approximately 341,000). Data have been aggregated across surveys.

LGBT IDENTIFICATION

LGBT identity is based on response to the question, "Do you, personally, identify as lesbian, gay, bisexual, or transgender?" Respondents who answered "yes" were classified as LGBT, those answering "no" were classified as non-LGBT. Those who did not answer the LGBT identity item (2017: 6.4% weighted, n=21,082; 2015-2017: 5.5% weighted, n=57,562; 2012-2017: 6.3% weighted, n=69,555), because they refused to answer the question or said "I don't know," were excluded from analyses; however, they are included in the denominator used to estimate % LGBT. All n's are unweighted.

NATIONAL (ALL AND FILTERED BY SEX)

Data from 2017 are presented. All proportions are weighted using Gallup post-stratification national sampling weights and allow estimates to be representative of the U.S. national population.

NATIONAL (FILTERED BY RACE)

Aggregated data from 2015-2017 are presented. All proportions are weighted using Gallup post-stratification national sampling weights and allow estimates to be representative of the U.S. national population.

STATE (ALL AND FILTERED BY SEX)

Aggregated data from 2015-2017 are presented for most states. Additional data collected from June 1, 2012 through December 31, 2017 were aggregated for 13 states with smaller samples (200 LGBT respondents in the 2015-2017 aggregated dataset): Alaska, Delaware, Hawaii, Idaho, Mississippi, Montana, New Hampshire, North Dakota, Rhode Island, South Dakota, Vermont, West Virginia, and Wyoming. All proportions are weighted using Gallup post-stratification state sampling weights that account for differences in 2017 survey sampling fractions.

UNSTABLE ESTIMATE

"*" Indicates an unstable estimate due to an insufficient sample size (n<30) and/or 95% confidence interval width as per suppression guidance provided in Parker JD, Talih M, Malec DJ, et al. National Center for Health Statistics Data Presentation Standards for Proportions. National Center for Health Statistics. Vital Health Stat 2(175). 2017.

GENDER

Respondents were classified as male or female, based on their response to the question, "I am required to ask, are you male or female?"

RAISING CHILDREN

Children in household, among adults age 25 and over, defined as > 1 child under the age of 18 living in the respondent's household. Only reported for respondents aged 25 and over. Question and sampling weight from the Gallup-Sharecare Well-Being Index survey only.

RACE AND ETHNICITY

Race/ethnicity was defined on the basis of responses to two questions -- Hispanic, Latino, or Spanish origin (yes/no) and race (chose all that apply.) Respondents who indicated that they are Hispanic, Latino, or of Spanish origin were classified as Latino/a or Hispanic and all non-Hispanic respondents were classified by race (single race or more than one race.) When estimates were unstable for specific racial/ethnic groups, these groups were aggregated and labeled all other races.

WHITE/ALL OTHER RACES

All other races includes respondents who were Latino/a or Hispanic, Black or African American, Asian, American Indian or Alaska Native, Native Hawaiian or other Pacific Islander, or more than one race. Dichotomized race/ethnicity is reported when estimates for six or more race/ethnicity categories are unstable.

AGE DISTRIBUTION

Dichotomized age is reported when estimates for more than one age category (18-24; 25-34; 35-49; 50-64; 65+) are unstable.

EDUCATIONAL ATTAINMENT

≤ High school includes respondents who obtained a high school diploma or GED certificate as well as those who did not complete high school. Some college includes respondents who obtained any post-secondary school technical, vocational or college training that did not yield a four-year Bachelor's degree. Bachelor's degree refers to a four-year degree from a college or university. > Bachelor's degree includes respondents who completed any schooling beyond the four-year degree.

COLLEGE EDUCATION

College education was defined as reporting having earned at least a four-year Bachelor's degree (including those earning a Bachelor's degree and any additional schooling) at the time they were surveyed. Only reported only for respondents aged 25 and over. Dichotomized college education is reported when two or more educational attainment categories (≤ High school; Some College; Bachelor's degree; Post-graduate) are unstable.

UNEMPLOYED

Employment status among respondents in the labor force was dichotomized as either employed (including full-time or part-time employment), or unemployed (those currently unemployed, but actively looking for work and able to work).

HEALTH INSURANCE

Question and sampling weight from the Gallup-Sharecare Well-Being Index only for 2012 through 2016, and from both Gallup surveys in 2017.

FOOD INSECURITY

Food insecurity was defined as ever "not having enough money to buy food that you or your family needed" in the past twelve months. Question and sampling weight from the Gallup-Sharecare Well-Being Index survey only.

HOUSEHOLD INCOME

In 2017, the poverty threshold for a family of four was slightly over $25,086. Source: U.S. Census Bureau. Preliminary Estimate of Weighted Average Poverty Thresholds for 2017.

About This Project

The **LGBT Data & Demographics** site was originally built and published in 2016 by The Williams Institute with support from the Ford Foundation and the assistance of designers and technology developers at TWO-N. The core team who created this work included **Angeliki Kastanis**, **Gary J. Gates**, and **Matt Strieker**. In 2018, **Shoshana Goldberg** and **Kerith Conron** added to this foundation and provided updated and expanded Gallup estimates about LGBT people to the site.

Contact: williamsinstitute@law.ucla.edu

Designed & developed by 2n

Preferred Citation:

LGBT Demographic Data Interactive. (January 2019).
Los Angeles, CA: The Williams Institute, UCLA School of Law.

Funders for LGBTQ Issues Special Report | January 2015

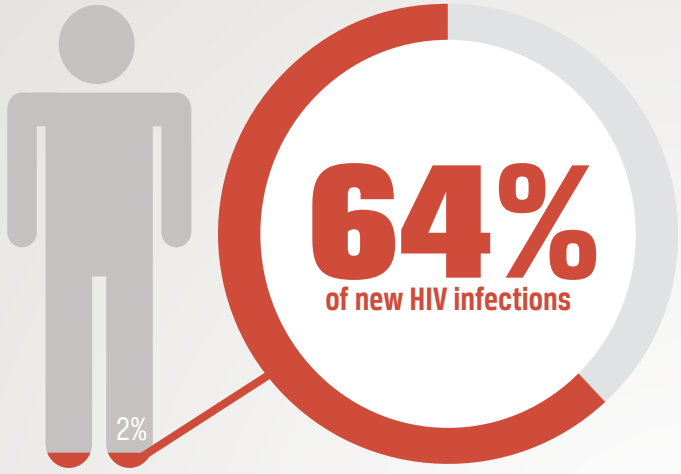
VITAL FUNDING

Investing in LGBTQ Health and Wellbeing

FUNDERS FOR LGBTQ ISSUES

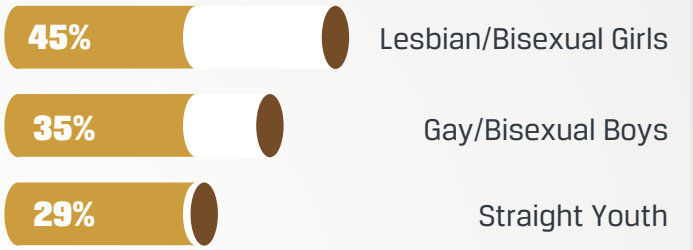
The Need

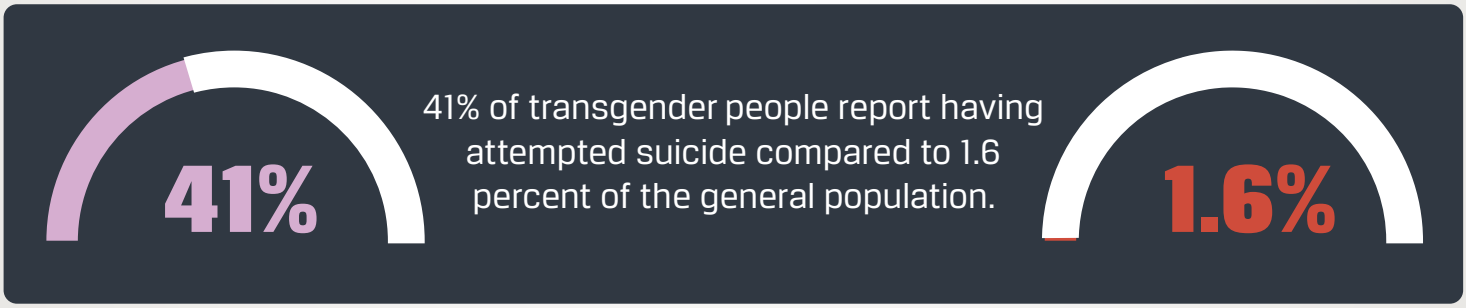
Like other minorities, lesbian, gay, bisexual, and transgender communities face significant health disparities.



Gay and bisexual men and other men who have sex with men account for **64 percent of new HIV infections** even though they make up only about 2 percent of the population.

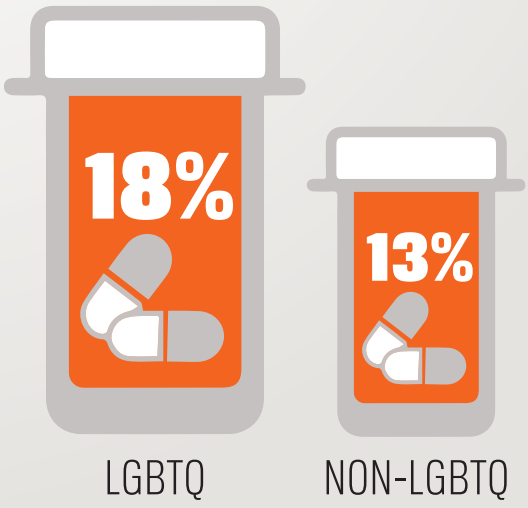
LGBTQ youth are more likely to smoke



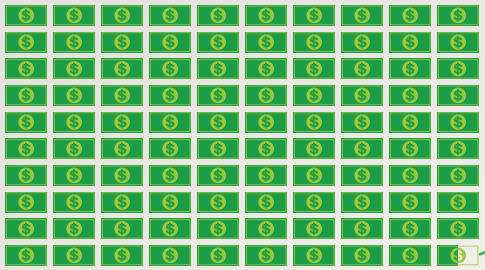


LGBTQ people are more likely to lack health insurance.

18% of LGBTQ adults have no health insurance compared to about 13% of non-LGBTQ adults

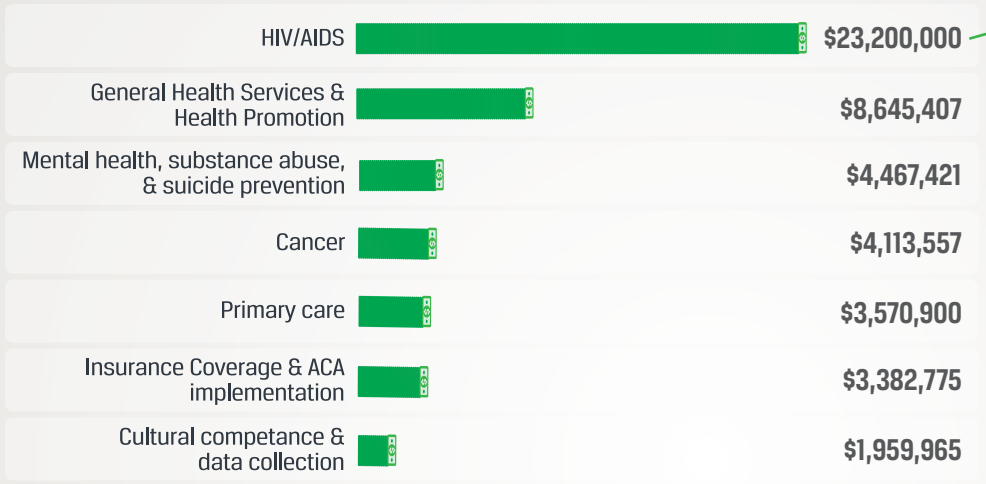


The Funding



Between 2011-2013, foundations and corporations awarded more than **$50 million for LGBTQ health**.

On average, less than one half of one percent of foundation funding for health is for LGBTQ communities.



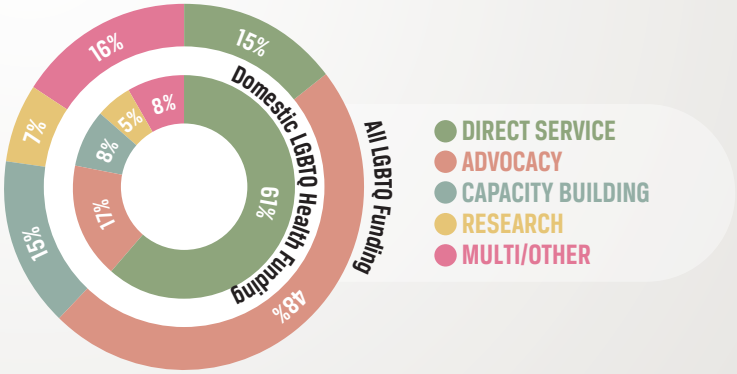
Of U.S. funding for HIV/AIDS, only 21% targets LGBTQ communities - although LGBTQ people account for the majority of new infections.

HEALTH ISSUES FUNDED

Nearly half of LGBTQ health funding was for HIV/AIDS prevention and treatment, with significant portions also devoted to primary care, mental health and substance abuse, cancer, and insurance coverage.

STRATEGIES FUNDED

While advocacy is the most commonly funded strategy for LGBTQ funding overall, **direct service is the most commonly funded strategy for LGBTQ health.**



The Opportunity

In a rapidly changing policy landscape for both healthcare and LGBTQ rights, funders concerned about health disparities, HIV/AIDS, and LGBTQ communities have **several unique opportunities for increased impact on LGBTQ health.**

- Explore Collaborative Efforts to Address Mental & Behavioral Health & Other Social Determinants Related to Stigma.
- Increase Access to Insurance Coverage for LGBTQ People.
- Build Capacity of the HIV/AIDS and LGBTQ Health Services Sector.
- Increase LGBTQ Cultural Competence of Health Service Providers and Systems.
- Strengthen HIV/AIDS and LGBTQ Health Policy and Advocacy Infrastructure.

INTRODUCTION

The movement for lesbian, gay, bisexual, transgender and queer (LGBTQ) rights has seen amazing progress in recent years, on issues ranging from the freedom to marry to inclusion in the military. Yet even with these advances in legal equality, many LGBTQ people still face basic challenges when it comes to quality of life. LGBTQ people are at greater risk for mental and behavioral health challenges, and for diseases such as HIV/AIDS and cancer. Many of us lack health insurance and face other barriers to accessing health care—especially among those who are transgender, people of color, undocumented or economically disadvantaged. In short, we are more likely to get sick, and we are less likely to get the care we need.

This report, *Vital Funding: Investing in LGBTQ Health and Wellbeing*, assesses the scale and character of foundation funding for the health and well-being of LGBTQ communities. Drawing on the data collected for our annual tracking reports on LGBTQ funding, we find that domestic foundation funding for LGBTQ health totaled $50.4 million for 2011 - 2013. Considering the magnitude of the health disparities facing LGBTQ communities, this is a fairly modest amount – and it is highly dependent on a small set of dedicated funders.

When it comes to LGBTQ health, we face daunting challenges, but we also have impressive assets to build on. As a community and as a movement, we have time and again demonstrated our ability to come together to support one another, to advocate for ourselves, and to build lasting institutions. Across the country, there are hundreds of LGBTQ community centers, health centers, and HIV/AIDS service agencies, and other community groups advancing LGBTQ health. There are also a growing number of non-LGBTQ-focused institutions—from hospitals to research centers—seeking to improve their competence, expertise, and effectiveness in working with LGBTQ communities.

In the philanthropic sector, LGBTQ health offers a unique opportunity for LGBTQ funders, HIV funders, and health funders to come together, to learn from each other, and to leverage grant dollars in creative ways. We are honored to have the support of the Robert Wood Johnson Foundation for this effort, and to have wonderful allies in organizations such as Funders Concerned About AIDS and Grantmakers In Health. We hope this report will provide a starting point for a broad and diverse group of funders to develop strategies for lasting and powerful impact on the health and wellbeing of LGBTQ communities.

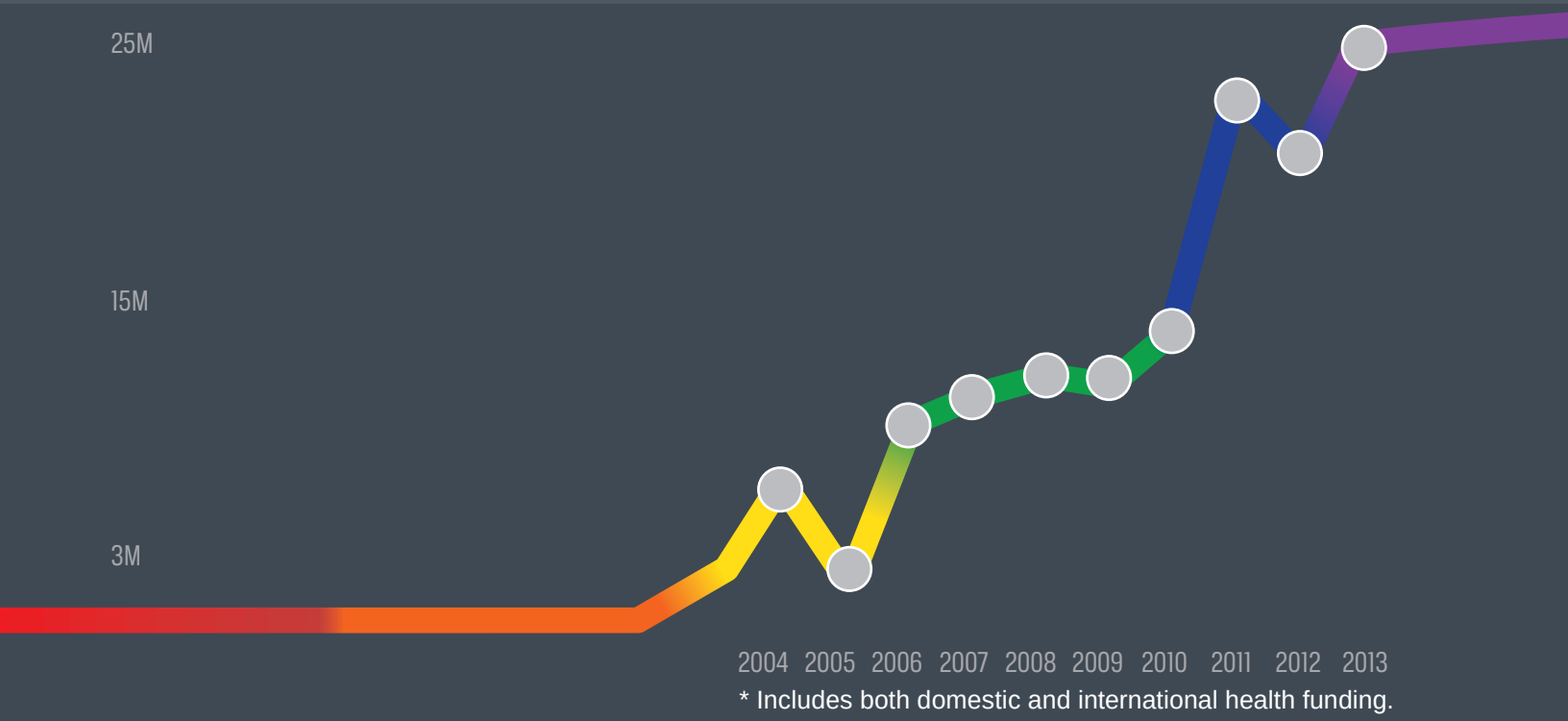
Take care,

Ben Francisco Maulbeck
President

Table of Contents

LGBTQ Health Funding

2004-2013



* Includes both domestic and international health funding.

The Need

HEALTH DISPARITIES

Like other minority groups, the LGBTQ community faces significant health disparities, particularly around issues of HIV, cancer, cardiovascular health, and mental health. These disparities tend to be especially severe among various LGBTQ subpopulations such as people of color, youth, older adults, and transgender people.

HIV

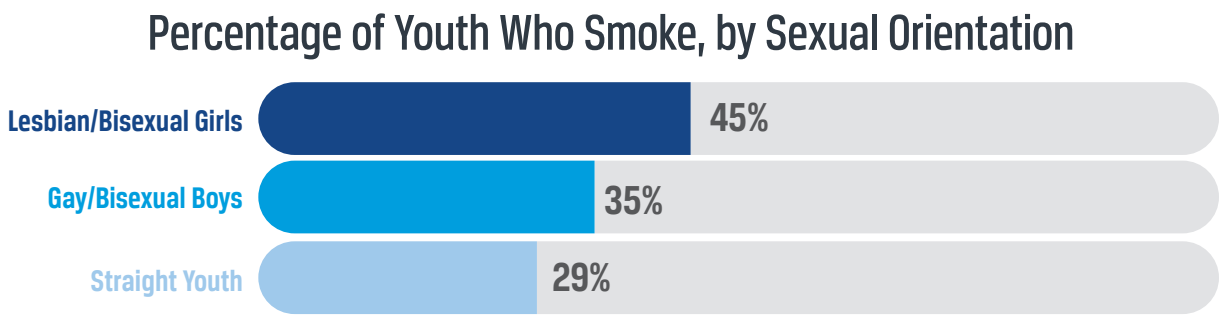
Despite decreasing HIV incidence rates in the general U.S. population, rates among men who have sex with men (MSM) and transgender women have continued to rise. In 2010, there was an estimated 12-percent increase in new infections among men who have sex with men, who accounted for more than three-quarters of new infections among men and nearly two-thirds of all new infections. There is an especially high prevalence among youth between 13-24 years of age, Black men, and Latino men.[1] Young Black gay and bisexual men showed the greatest increase of new cases from 2008-2011.[2] Among transgender women, the incidence is more difficult to estimate because gender identity is not tracked by most data collection sources. Still, we know that transgender people, and African American trans women in particular, face severe risks of HIV. Based upon a 2008 meta-analysis of 29 studies focusing on trans health, 28 percent of trans women tested positive for HIV. When adjusted for population size, trans women are nearly twice as likely as gay and bisexual men to contract HIV.[3] Gay men and trans people not only face these higher rates of infection, but are also more likely to face obstacles to diagnosis and treatment.

Cancer

Due to higher rates of obesity, smoking, alcohol consumption, and delayed engagement in preventative healthcare, LGBTQ people are at increased risk for developing various types of cancer. LGBTQ people are at higher risk for both colon cancer and lung cancer. Lesbians and bisexual women are at increased risk for breast cancer and gynecological cancers. Gay and bisexual men face increased risk for both prostate cancer and anal cancer. One major contributor to increased risk for gynecological cancers, anal cancer, and, in some cases, oral cancers is HPV. Many members of the LGBTQ community perceive low risk regarding HPV and are less inclined to have Pap smears or anal Pap tests, which is critical to detecting potential symptoms of HPV, gynecological cancers, and anal cancer.[4] It is hard to assess the specific numbers of cancer-related cases in the LGBTQ community, given that no large national data has been collected on sexual orientation or gender identity among the major cancer-related entities; improved data collection on sexual orientation and gender identity around cancer would enable development of more targeted strategies for prevention and early treatment of cancers in LGBTQ communities.

Substance Abuse

Disparities around HIV, cancer and other health conditions can be attributed in part to behavioral risk factors such as substance use and addiction, particularly tobacco and alcohol use. LGBTQ people are 2-3 times more likely to be addicted to tobacco compared to general population. It is estimated that over 30,000 LGBTQ people die annually because of tobacco-related causes. A recent adolescent health survey found that same-sex attracted individuals were more likely to smoke (45 percent of girls and 35 percent of boys) compared to other youth (29 percent).[5] Additionally, it is estimated that approximately 30 percent of gays and lesbians have substance abuse problems related to alcohol. LGBTQ youth are almost 200 percent more likely to use substances compared to heterosexual youth.[6] This contributes to various types of cancer, cardiovascular health concerns, and sexual health risks resulting from behavioral choices made while under the influence.



Mental Health

In part, higher rates of substance abuse among LGBTQ people are tied to coping strategies in the face of discrimination and stigma, as well as historical socialization processes and community-building opportunities that most often occurred in bars and clubs. LGBTQ individuals are more likely to report feelings of depression and anxiety. In fact, it is estimated that close to 720,000 LGBTQ community members suffer from serious mental illness.[7] LGBTQ people have higher rates of suicide and attempts, especially among transgender people—41 percent of whom report attempting suicide at some point in their lives, compared to 1.6 percent of the general population.[8] These mental health challenges are even more prevalent among youth and elders.

SOCIAL DETERMINANTS OF HEALTH

Social determinants are environmental factors—whether place-based or sociocultural—that contribute to health outcomes. Many of the health disparities faced by LGBTQ communities are due to inequities related to social determinants. The LGBTQ community has been subjected to a long history of legal inequality, social marginalization, and other forms of discrimination based on sexual orientation or gender identity. These systems of discrimination have resulted in inequities around housing access, employment and socioeconomic status, and other stresses, which in turn contribute to poor health.

Homelessness

It is estimated that LGBTQ youth make up to 40 percent of the homeless youth population.[9] Within this population of LGBTQ homeless youth, nearly two-thirds are people of color.[10] Many more LGBTQ youth are also in the fostercare and the juvenile justice system. The high rate of homelessness among LGBTQ youth is in part attributable to lack of family acceptance and fears of repercussions for coming out.

Family Rejection

Not only can family rejection directly lead to problems such as homelessness, it also has long-term health consequences. Researchers have found that LGBTQ people who are rejected by their families in adolescence are more likely to experience depression, low self-esteem, substance abuse, and other health problems in adulthood. LGBTQ people who feel rejected by their families in their youth are more than twice as likely to have suicidal ideations in their adulthood.[11]

Poverty and Unemployment

LGBTQ people are more likely to live in poverty compared to the general population. Thirty-two percent of LGBTQ individuals have household incomes of less than $24,000, compared to 24 percent of non-LGBTQ people with incomes of less than $24,000.[12] Transgender people, youth, women, and African Americans face particularly severe income disparities.[12] A large segment of the LGBTQ community is also underemployed or unemployed. Transgender individuals are the most impacted, as they are often discriminated against by employers or potential

employers and lack explicit legal protections in most jurisdictions. In fact, 44 percent of transgender individuals are underemployed, and they are twice as likely to be unemployed.[13] LGBTQ individuals also have higher living costs because they are often ineligible for various incentives and tax breaks afforded to heterosexual married couples. Additionally, gay families on average have the lowest annual incomes and often do not qualify for some federal assistance programs like WIC.[14]

Violence and Bullying

Based on reports from LGBTQ-focused anti-violence programs, more than 2,000 LGBTQ people were the victims of hate-motivated violence in 2013. Only 45 percent of these survivors of violence reported the incident to the police; of those who did report, nearly one-third reported hostility, being unjustly arrested, being subjected to excessive force, or other forms of police misconduct.[13] LGBTQ people also experience high levels of intimate-partner violence. Forty-four percent of lesbians and 61 percent of bisexual women have experienced intimate-partner violence, compared to 35 percent of heterosexual women.[14] LGBTQ youth are also more likely to face violence and other forms of bullying. Eighteen and a half percent of gay and lesbian high school students and 15.5 percent of bisexual students reporting threatened or injured with a weapon on school property, compared to 6.1 percent of heterosexual students.[15] These experiences of bullying, hate violence, and intimate partner violence are likely to contribute to depression and other mental health challenges, difficulties accessing care, and to other social determinants such as economic security.

Delayed Care

LGBTQ individuals are less likely to engage in preventive health and treatment services. Delayed engagement in health care is a leading cause for many of the poor health outcomes plaguing the LGBTQ community. LGBTQ individuals report feeling their healthcare providers are less culturally responsive and understanding of their needs. This causes some to avoid healthcare engagement or for those engaging in care to not disclose their sexual and/or gender identity for fear of discrimination.

HEALTH INSURANCE COVERAGE

Lack of health insurance is another major factor contributing to poor health outcomes for LGBTQ people. Nearly 18 percent of LGBTQ adults have no health insurance compared to about 13 percent of non-LGBTQ adults.[16] Legal inequality contributes to this gap; in states that do not recognize marriage equality or same-sex partnerships, LGB people are unable to attain health insurance through a same-sex spouse's employer. Advancements in marriage equality and the Affordable Care Act (ACA) have helped increase the number of LGBTQ people with health insurance. Among LGBTQ people living below 400 percent of federal poverty guidelines, the ACA has decreased the uninsured population from 34 percent to 26 percent.[17] Despite this progress, LGBTQ people face discrimination and unique barriers to accessing health insurance coverage in many jurisdictions. Transgender people face particularly severe barriers when it comes to insurance; more than one-third have no health insurance, even after the first year of the ACA's full implementation. Even among those who do have health insurance, they are often denied coverage by health plans that exclude necessary medical care for transgender people.[18]

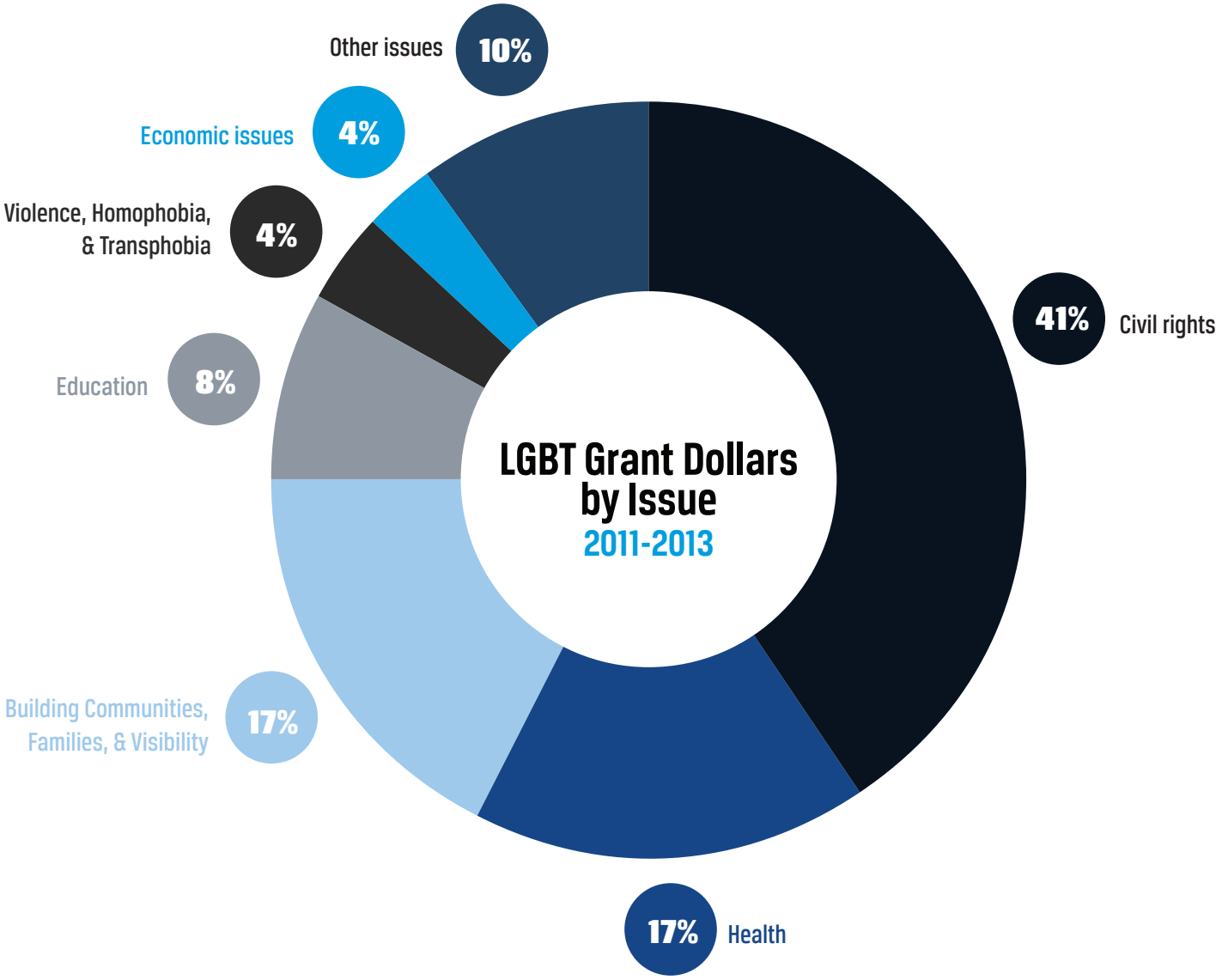
Percentage of Uninsured Adults, by Sexual Orientation and Gender Identity

Overview of LGBTQ Health Funding

U.S. FOUNDATION FUNDING FOR LGBTQ HEALTH ISSUES

In 2011-2013, foundations awarded 1,757 grants totaling $50.4 million for LGBTQ health in the U.S. Nearly half (46 percent) of these grant dollars were for HIV/AIDS, and the remaining 54 percent addressed health issues ranging from breast cancer to mental health and suicide prevention.

Health captured about 17 percent of the total $301 million in domestic LGBTQ funding for 2011-2013. This makes health the second most-funded LGBTQ issue—though it is a distant second, capturing a much smaller portion than the 41 percent for civil rights.



In the context of overall foundation funding for health, only a tiny fraction specifically targets LGBTQ communities. In 2011, foundations awarded $3 billion in grants for health in the U.S.[19] Domestic LGBTQ health funding that year was approximately $16 million, or about one half of one percent of the total. Even in the context of HIV/AIDS, only about 21 percent of HIV/AIDS funding targets gay, bisexual, and transgender communities, even though LGBTQ people account for the majority of new infections in the U.S.[20]

Who is funding LGBTQ health?

SOURCES OF LGBTQ HEALTH FUNDING

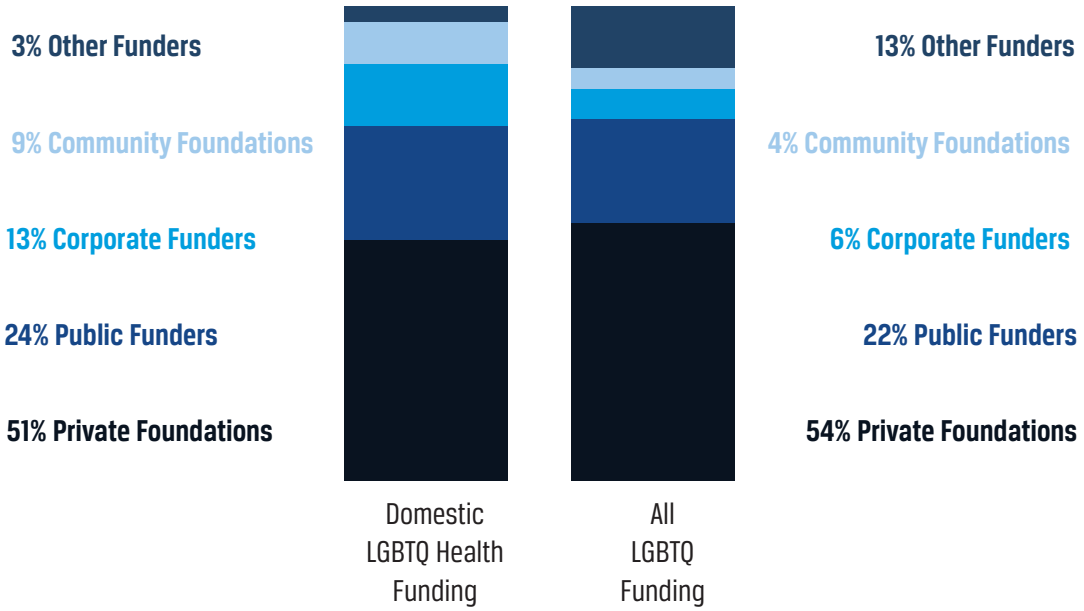
As with LGBTQ funding overall, the majority of domestic LGBTQ health funding (51 percent) is provided by private foundations. The second largest share of LGBTQ health funding (24 percent) comes from various public funders—including public LGBTQ foundations as well as public HIV/AIDS foundations, such as the Elton John AIDS Foundation.

Notably, a larger share of LGBTQ health funding comes from corporate funders, which provide 13 percent of domestic LGBTQ health funding but only 6 percent of LGBTQ funding overall. This trend is largely driven by several corporate funders that are among the top HIV/AIDS funders, such as Levi-Strauss & Co., the M.A.C. AIDS Fund, and Wells Fargo.

Community foundations also provide a larger share of LGBTQ health funding (9 percent) than they do for LGBTQ funding overall (4 percent). This is largely because a number of community foundations have invested in health services for LGBTQ communities in their local area, both for HIV/AIDS and for health needs more broadly.

Sources of LGBTQ Health Funding by Type of Funder

2011-2013



	Domestic LGBTQ Health Funding	All LGBTQ Funding
Private Foundations	$25,730,262	$220,873,346
Public Funders	$12,276,686	$90,066,522
Corporate Funders	$6,545,284	$25,757,222
Community Foundations	$4,504,809	$17,308,575
Other Funders	$1,740,000	$53,422,810
Grand Total	**$50,797,041**	**$407,428,475**

*This chart includes funds intended for regranting.

The top 25 funders awarded a total of $35.6 million in grants for LGBTQ health, accounting for about 70 percent of all LGBTQ health funding in 2011-2013. This group of 25 funders is more diverse than the list of top LGBTQ funders overall, including not only LGBTQ-specific funders but also a number of HIV funders, broadly-focused health funders, community foundations, and corporate funders.

Top 25 LGBTQ Health Funders, 2011 - 2013		
1.	Elton John AIDS Foundation, New York, NY	$4,317,556
2.	Ford Foundation, New York, NY	$4,312,000
3.	Susan G. Komen Foundation, Dallas, TX	$4,000,007
4.	M.A.C. AIDS Fund, New York, NY	$2,942,789
5.	The California Endowment, Los Angeles, CA	$2,750,773
6.	AIDS United, Washington, DC	$1,757,100
7.	Anonymous, Various Locations	$1,741,000
8.	Harry and Jeanette Weinberg Foundation, Owing Mills, MD	$1,500,000
9.	Arcus Foundation, New York, NY	$1,272,780
10.	Keith Haring Foundation, New York, NY	$1,235,000
11.	Wells Fargo Foundation, Palm Springs, CA	$1,197,355
12.	New York Community Trust, New York, NY	$1,063,150
13.	Jewish Communal Fund, New York, NY	$1,035,690
14.	The Paul Rapoport Foundation, New York, NY	$899,500
15.	Houston Endowment, Houston, TX	$690,000
16.	GE Foundation, Fairfield, CT	$600,000
17.	Levi Strauss & Co. Foundation, San Francisco, CA	$596,000
18.	Henry van Ameringen Foundation, New York, NY	$595,000
19.	San Francisco Foundation, San Francisco, CA	$548,500
20.	Healthcare Foundation of New Jersey, Millburn, NJ	$457,000
21.	Horace W. Goldsmith Foundation, New York, NY	$450,000
22.	Greater Milwaukee Foundation, Milwaukee, WI	$438,243
23.	Black Tie Dinner, Dallas, TX	$435,810
24.	District of Columbia Bar Foundation, Washington, DC	$424,000
25.	Chicago Community Trust, Chicago, IL	$390,550

What is being funded in LGBTQ health?

SPECIFIC HEALTH ISSUES FUNDED

The $27.4 million in LGBTQ health funding (other than HIV/AIDS) for 2011-2013 addressed a range of health issues, with no other issue capturing more than 20 percent of total dollars.

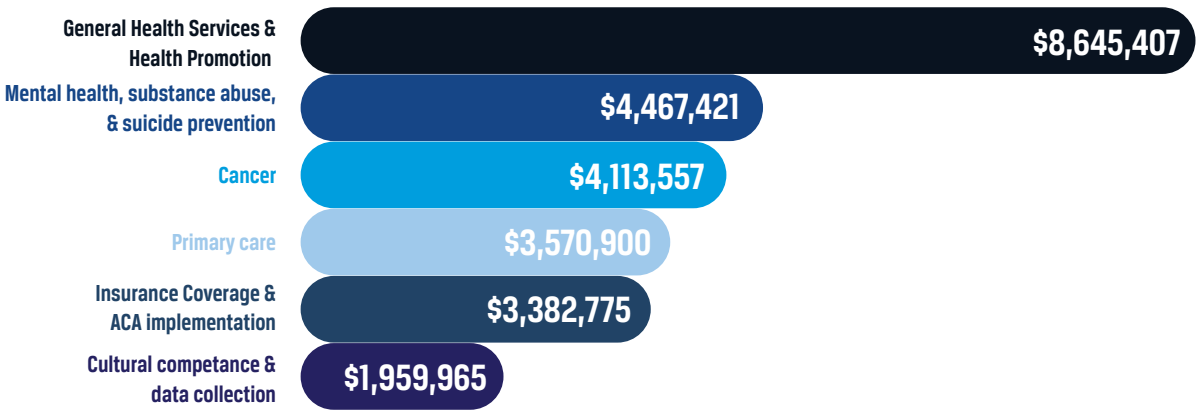
- The largest share of dollars ($8.6 million, or 17 percent of the total) went to **general health services and health promotion**, such as those offered by LGBTQ community centers, and for activities ranging from health fairs to community wellness campaigns to advance the health of LGBTQ communities.
- **Mental health, substance abuse, and suicide prevention** collectively received $4.5 million for activities ranging from suicide hotlines to addiction recovery programs.
- Services and research related to **breast cancer** and other cancers received about $4.1 million, the bulk of it from the Susan G. Komen Foundation.
- More than $3.3 million were devoted to activities related to **insurance coverage** and **implementation of the Affordable Care Act**, largely for outreach to enroll LGBTQ people in new insurance coverage options and for advocacy for LGBTQ-inclusive policies in the establishment of state health care exchanges.
- More than $3.5 million were devoted to **primary care**, largely for general support of LGBTQ health clinics and other primary care providers specifically targeting LGBTQ communities.
- **Cultural competence and data collection** received almost $2 million for data collection on LGBTQ health care needs and training of health care providers on effectively serving LGBTQ communities.
- Smaller amounts were devoted to sexual and reproductive health ($682,981), child welfare/foster care ($465,073), smoking cessation ($191,271), and food and nutrition ($108,520).

The above breakdown, however, may underestimate the level of support for certain health issues. In particular, a significant portion of HIV/AIDS grant dollars by their nature also address other health issues affecting LGBTQ communities. For example, HIV/AIDS prevention activities often address issues of mental health, addiction, and sexual and reproductive health. Similarly, many primary care providers and health service providers also offer HIV/AIDS treatment.

The wide range of issues addressed are reflected in the list of top 25 LGBTQ health grantees for 2011-2013, which include organizations addressing issues such as HIV/AIDS, reproductive health, health care reform, primary care, aging, suicide prevention, and breast cancer.

LGBTQ Health Funding by Specific Health Issue Funded

excluding HIV/AIDS, 2011-2013



Top 25 LGBTQ Health Grantees, 2011 - 2013		
1.	GMHC, New York, NY	$2,895,364
2.	SAGE, New York, NY	$2,225,000
3.	Kaiser Family Foundation, Menlo Park, CA	$1,250,000
4.	Callen-Lorde Community Health Center, New York, NY	$1,218,899
5.	AIDS Project Los Angeles, Los Angeles, CA	$1,078,287
6.	Planned Parenthood of New York City, New York, NY	$1,030,000
7.	Trevor Project, Palm Springs, CA	$1,011,976
8.	How to Survive a Plague, New York, NY	$950,000
9.	Hetrick-Martin Institute, New York, NY	$902,500
10.	Howard Brown Health Center, Chicago, IL	$896,321
11.	San Francisco AIDS Foundation, San Francisco, CA	$893,020
12.	Community Catalyst, Boston, MA	$875,000
13.	Legacy Community Health Services, Houston, TX	$810,000
14.	Fenway Community Health Center, Boston, MA	$796,976
15.	AIDS Foundation of Chicago, Chicago, IL	$694,760
16.	Mautner Project, Washington, DC	$555,163
17.	Transgender Law Center, San Francisco, CA	$543,000
18.	National Foundation for the Centers for Disease Control and Prevention, Atlanta, GA	$520,280
19.	Regents of the University of Michigan, Ann Arbor, MI	$513,000
20.	Asian & Pacific Islander Coalition on HIV-AIDS, New York, NY	$512,000
21.	Equality California Institute, West Hollywood, CA	$500,000
22.	Mazzoni Center, Philadelphia, PA	$483,538
23.	Lyon-Martin Health Services, San Francisco, CA	$466,784
24.	Lesbian, Gay, Bisexual & Transgender Community Center, New York, NY	$440,658
25.	Illinois Caucus for Adolescent Health, Chicago, IL	$402,000

TARGET POPULATIONS

LGBTQ health funding is exceptionally likely to target specific populations: 77 percent of LGBTQ health grant dollars are directed toward a specific racial group, sexual or gender identity, age group, or other demographic. This reflects philanthropic responses to specific health disparities faced by particular identity groups.

For sexual orientation and gender identity, gay men and men who have sex with men were the target population of the largest share of dollars—$10.8 million. Ninety-six percent of these dollars were for HIV/AIDS treatment and prevention. The second largest share of LGBTQ health funding targeted lesbians and other queer-identified women: $4 million, 83 percent of which was for breast cancer. About $2.9 million targeted transgender people, 34 percent of which was to advance inclusive health insurance coverage and health care reform implementation. Only $82,500 targeted intersex communities. No known LGBTQ health grants explicitly targeted bisexuals, although some of the funding targeting gay men and men who have sex with men undoubtedly supported services for significant numbers of bisexual-identified men.

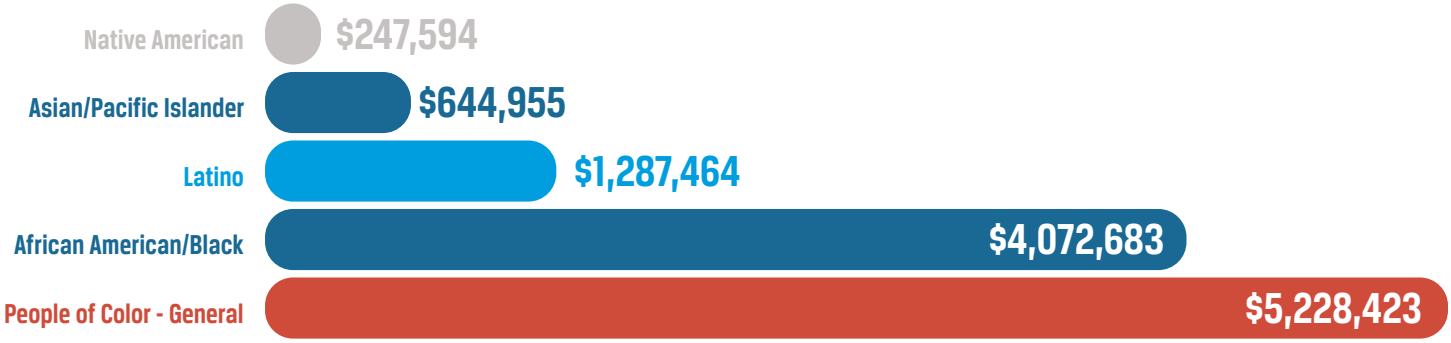
LGBTQ Health Grant Dollars Targeting Specific Sexual & Gender Identities

2011-2013

Nearly $11.4 million—or 22 percent of LGBTQ health funding—targeted LGBTQ communities of color. Approximately $4 million targeted African Americans, and another $5.2 million targeted communities of color broadly, with smaller amounts focused on Latinos, Asian American/Pacific Islanders, and Native Americans. HIV/AIDS funding accounts for the majority of LGBTQ health grant dollars targeting communities of color.

LGBTQ Health Grant Dollars Targeting People of Color

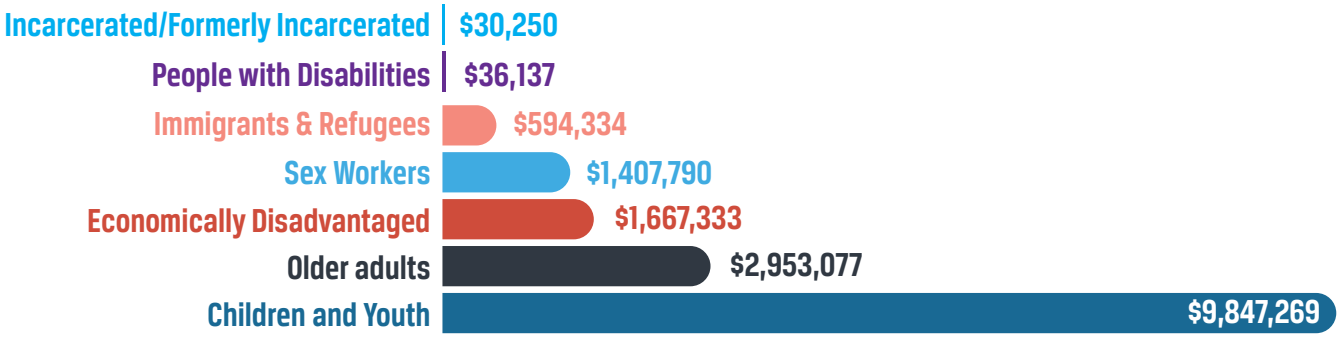
2011-2013



Significant LGBTQ health grant dollars targeted several other key population groups. In particular, $9.8 million targeted LGBTQ children and youth, and nearly $3 million targeted LGBTQ older adults. Nearly $1.7 million of LGBTQ health funding focused on the economically disadvantaged, and about $1.4 million specifically focused on sex workers.

LGBTQ Health Grant Dollars Targeting Other Populations

2011-2013

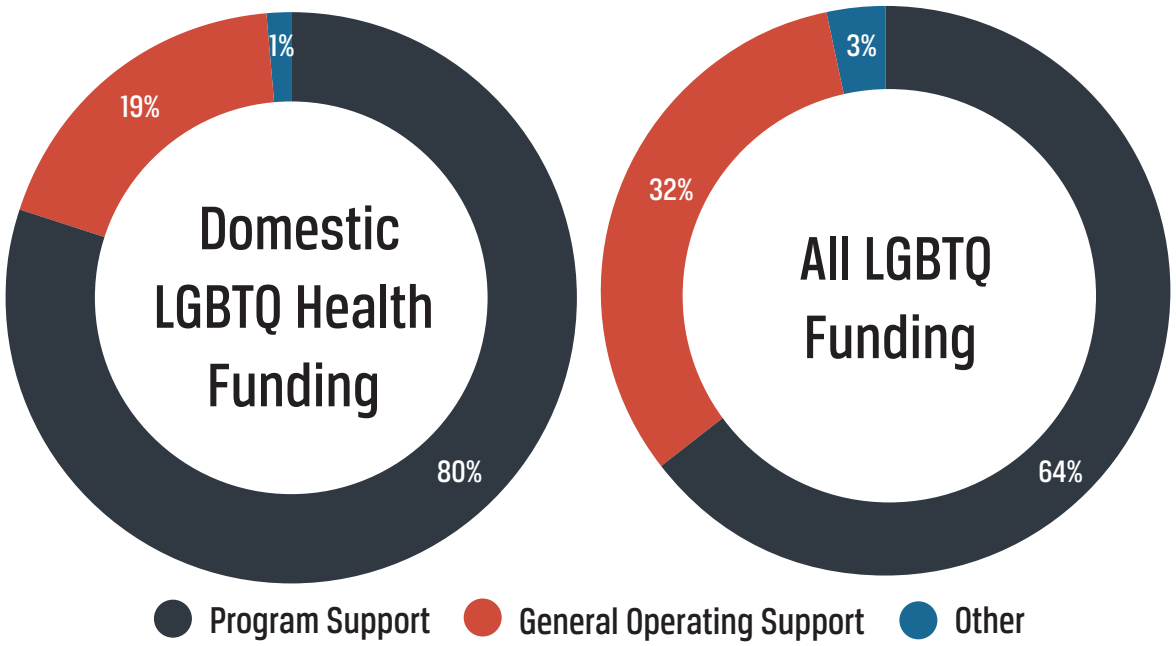


TYPE OF SUPPORT

About four-fifths of domestic LGBTQ health funding is for the support of a specific program, with the remaining fifth devoted to general operating support. LGBTQ health funding is more likely to be for programmatic support compared to overall LGBTQ funding, which sees 64 percent of grant dollars devoted to program support.

Distribution of Grant Dollars by Type of Support

2011-2013



	Domestic LGBTQ Health Funding		All LGBTQ Funding	
Program support	$40,440,003	80%	$240,907,485	64%
General operating support	$9,378,205	19%	$120,387,618	32%
Other	$670,796	1%	$12,241,889	3%
	$50,489,005	**100%**	**$373,536,992**	**100%**

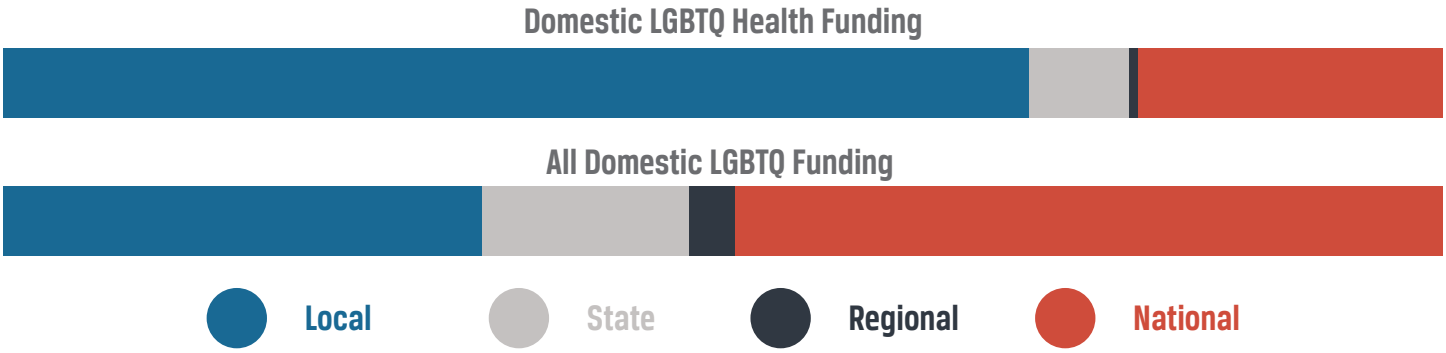
GEOGRAPHIC FOCUS

The vast majority of LGBTQ health funding—79 percent—is locally focused, and 21 percent is national in focus. The geographic focus of LGBTQ health funding is closely tied to the strategy funded; 80 percent of local dollars are devoted to direct services, and 41 percent of national dollars are devoted to advocacy.

In contrast, for all LGBTQ funding overall, a full half of dollars are devoted to national work, much of it for policy and advocacy.

Distrubution of Grant Dollars by Geographic Focus

2011-2013



	Domestic LGBTQ Health Funding 2011-2013		All Domestic LGBTQ Funding 2011-2013	
Local	$35,970,099	71%	$99,813,753	33%
State	$3,474,128	7%	$43,166,929	14%
Regional	$332,325	1%	$9,467,561	3%
National	$10,712,452	21%	$147,743,087	50%
	$50,489,005	**100%**	**$300,191,330**	**100%**

Of the approximately $40 million awarded to LGBTQ health at the local, state, and regional levels, the largest share ($17.5 million) was devoted to the Northeast region. The Midwest, the Mountain states, and the South received much lower dollar amounts, especially in proportion to their populations.

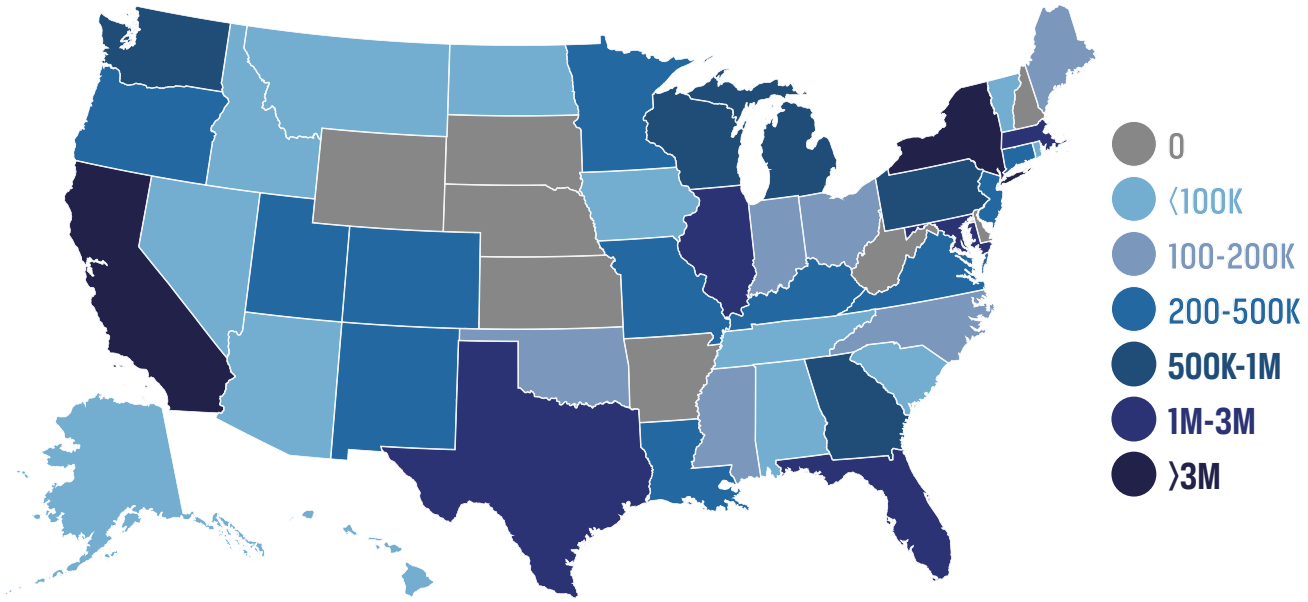
State and Local Funding for LGBTQ Health by Target Region 2011 - 2013	
Northeast	$17,530,257
Pacific	$8,940,507
South	$6,819,008
Midwest	$5,503,932
Mountain	$928,833
U.S. Territories	$40,000

Note: Does not include $14,015 awarded to anonymous individuals in undisclosed regions.

In most of these regions, much of the funding was concentrated in just one or two states. In the Northeast, the majority of funding ($11.1 million) was focused on New York. More than 88 percent of funding for the Pacific was for California—three-quarters of which was provided by funders based in California, such as The California Endowment and The California Wellness Foundation. Nearly half of Midwest funding went to Illinois, and nearly 60 percent of Southern funding focused on Florida or Texas. Each of these relatively well-funded states is home to major urban centers with large LGBTQ communities and a number of HIV/AIDS and LGBTQ-focused service providers. The disparities between states points to the challenges of addressing LGBTQ health issues outside of urban centers, and to the need for deeper engagement of more local funders in states beyond the coasts.

State and Local Funding for LGBTQ Health by Target State

2011-2013



Alabama	$34,000	Illinois	$2,600,698	Missouri	$262,352	Pennsylvania	$885,307
Alaska	$500	Indiana	$145,500	Montana	$28,100	Puerto Rico	$40,000
Arizona	$66,650	Iowa	$1,000	Nevada	$50,855	Rhode Island	$23,650
California	$7,904,237	Kentucky	$408,015	New Jersey	$399,122	South Carolina	$25,000
Colorado	$213,226	Louisiana	$306,000	New Mexico	$336,338	Tennessee	$46,000
Connecticut	$403,906	Maine	$138,780	New York	$11,121,399	Texas	$2,630,548
District of Columbia	$1,546,271	Maryland	$1,805,532	North Carolina	$146,850	Utah	$201,164
Florida	$1,401,500	Massachusetts	$1,131,790	North Dakota	$60,000	Vermont	$74,500
Georgia	$821,429	Michigan	$977,552	Ohio	$102,951	Virginia	$381,341
Hawaii	$6,073	Minnesota	$408,369	Oklahoma	$158,500	Washington	$624,392
Idaho	$32,500	Mississippi	$170,000	Oregon	$362,806	Wisconsin	$945,510

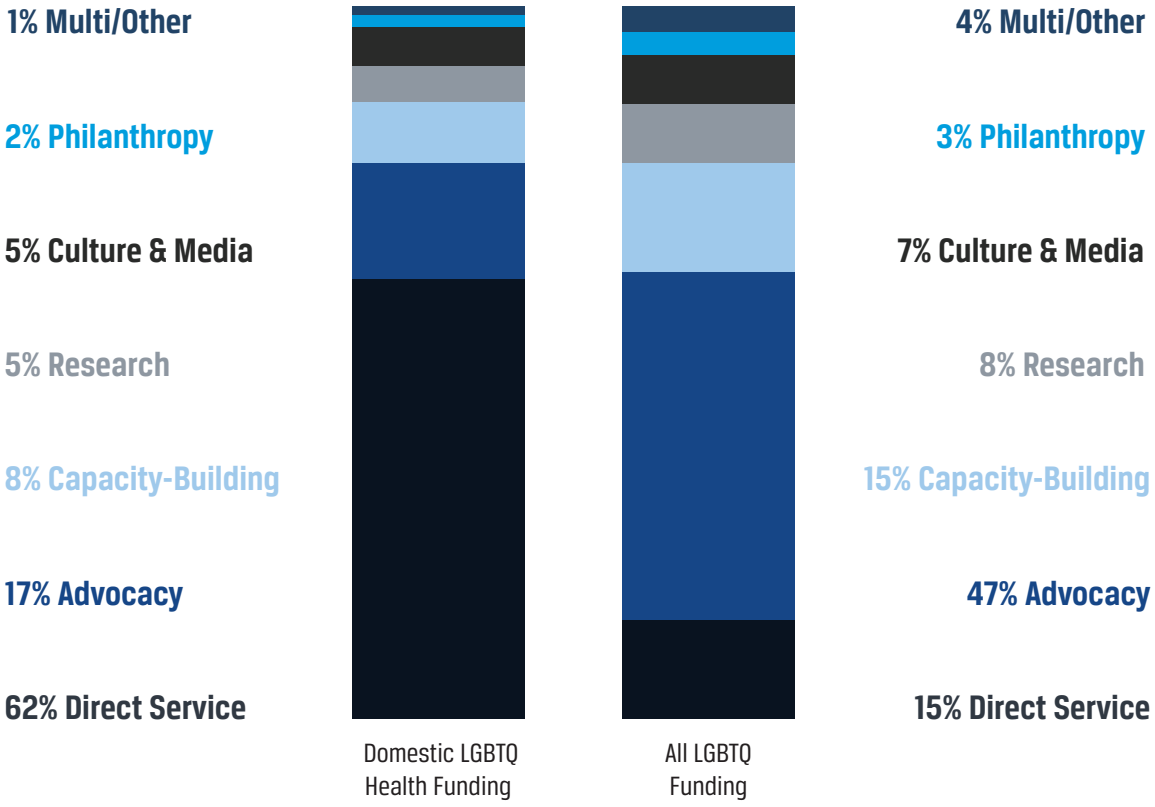
Note: Does not include $14,015 awarded to anonymous individuals in undisclosed regions.

STRATEGY

Looking at LGBTQ health funding by the types of strategies funded, **direct services** garnered the majority (62 percent) of grant dollars. This was followed by **advocacy** (17 percent), **capacity building and training** (8 percent), **research** (5 percent) and **culture and media** (5 percent). In contrast, advocacy is the predominant strategy for LGBTQ funding overall, followed by capacity building, and then by direct services.

Distribution of Grant Dollars by Strategy

2011-2013



	Domestic LGBTQ Health Funding		All LGBTQ Funding	
Direct Service	$31,052,701	62%	$54,413,570	15%
Advocacy	$8,465,454	17%	$177,332,672	47%
Capacity Building	$4,108,713	8%	$55,790,537	15%
Culture & Media	$2,730,268	5%	$25,635,432	7%
Research	$2,453,134	5%	$31,474,497	8%
Philanthropy & Fundraising	$930,475	2%	$12,774,393	3%
Multiple/Other Strategies	$748,260	1%	$13,670,682	4%
	$50,489,005	**100%**	**$371,091,783**	**100%**

Funding Opportunities

RECOMMENDATIONS

This report is largely intended as a starting point for a longer assessment and series of conversations about potential high-impact funding strategies to improve the health and well-being of LGBTQ communities. However, the data herein do highlight several key gaps and opportunities for funders seeking to advance health and wellbeing in LGBTQ communities.

Explore Collaborative Efforts to Address Mental and Behavioral Health and Other Social Determinants Related to Stigma

LGBTQ communities face an especially severe disease burden in mental and behavioral health. These challenges are driven by the stigma and marginalization related to homophobia and transphobia, which are also key social determinants of HIV/AIDS and other health disparities. This is an area that relates to the priorities of a range of funders, including LGBTQ-focused funders, HIV/AIDS funders, and funders broadly concerned about health disparities and inequity.

Increase Access to Insurance Coverage for LGBTQ People

The Affordable Care Act is rapidly shifting the health policy landscape and increasing access to health insurance. Funders have an opportunity to assure that coverage outreach efforts reach LGBTQ populations, and that insurance providers do not discriminate against LGBTQ people—especially when it comes to medical care for transgender people.

Build Capacity of the HIV/AIDS and LGBTQ Health Services Sector

There is a rich array of community-based organizations providing health services specifically for the LGBTQ community, including HIV/AIDS service organizations, LGBTQ health centers, community centers, and counseling and referrals hotlines. These service providers have unparalleled cultural competence when it comes to serving LGBTQ communities. However, many lack the resources to meet the full range of needs of their communities or are heavily reliant on one or a handful of government contracts. Particularly given the current shifting health policy climate, funders have an opportunity to build the capacity of these agencies, to expand the scope of their work and to develop sustainable revenue strategies.

Increase LGBTQ Cultural Competence of Health Service Providers and Systems

Many LGBTQ people may never be able to take advantage of LGBTQ-focused service providers, particularly in rural and less densely populated areas. Funders have an opportunity to support training, curriculum development, and other efforts to increase the cultural competence of hospitals, health centers, and other mainstream health care providers, so as to maximize their ability to effectively serve LGBTQ communities. Key areas include increasing competence in providing transition-related care for transgender people and providing sexual health and HIV prevention services that are sensitive, relevant, and empowering for LGBTQ communities.

Strengthen HIV/AIDS and LGBTQ Health Policy and Advocacy Infrastructure

The LGBTQ movement has built a fairly robust set of organizations for policy advocacy at the national and state levels, but much of this infrastructure has focused on civil rights issues such as marriage equality and protections from discrimination. Much of the HIV/AIDS infrastructure in the U.S. has shifted to a services focus, with only a small number of organizations focused on advocacy for people living with HIV. Funders have an opportunity to support LGBTQ and HIV/AIDS organizations in building advocacy programs around the health policy issues that affect LGBTQ communities, including inclusive implementation of ACA exchanges, repeal of HIV criminalization laws, improving data collection on sexual orientation and gender identity, and providing government funding for health services for LGBTQ communities.

NOTES

1. Department of Health & Human Services: "HHS LGBT Issues Coordinating Committee 2013 Report" (2013). See: http://www.hhs.gov/lgbt/resources/reports/health-objectives-2013.html

2. The Centers for Disease Control: "HIV Among African American Gay and Bisexual Men" (2014). See:http://www.cdc.gov/hiv/risk/racialethnic/bmsm/facts/

3. Center of Excellence for Transgender Health: "Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care & Services" (2014). See: http://transhealth.ucsf.edu/trans?page=lib-data-collection

4. National LGBT Cancer Network: "Cancer and the LGBT community" (2013). See: http://www.cancer-network.org/cancer_information/cancer_and_the_lgbt_community/

5. National LGBT Tobacco Control Network: "Cold Hard Truth" (2014). See: http://www.lgbttobacco.org/truth.php

6. LGBT Drug Rehab: "Gay and Lesbian Addiction Treatment Statistics" (2014). See: http://lgbtdrugrehab.com/addiction-treatment-statistics/

7. National Alliance on Mental Illness: "Mental Health Issues among Gay, Lesbian, Bisexual, and Transgender (GLBT) People" (2007). See: http://www.nami.org/Content/ContentGroups/Multicultural_Support1/Fact_Sheets1/GLBT_Mental_Health_07.pdf

8. Divison of Gender, Sexuality & Health at the NYS Psychiatric Institute and the Columbia University Department of Psychiatry: "LGBT Health: The Issues" (2014). See: http://gendersexualityhealth.org/LGBT/LGBTHealthIssues.html

9. The Williams Institute: "America's Shame: 40% of Homeless Youth are LGBT Kids" (2012). See: http://williamsinstitute.law.ucla.edu/press/americas-shame-40-of-homeless-youth-are-lgbt-kids/

10. Advocates for Youth: "The Impact of Homophobia and Racism on LGBTQ Youth of Color." (2007). See: http://www.lgbt.ucla.edu/documents/ImpactofHomophobiaandRacism_000.pdf

11. Ryan, Caitlin; Stephen T. Russell; David Huebner; Rafael Diaz; and Jorge Sanchez; "Family Acceptance in Adolescence and the Health of LGBT Young Adults," Journal of Child and Adolescent Psychiatric Nursing Volume 23, Number 4 (2010). See: http://familyproject.sfsu.edu/files/FAP_Family%20Acceptance_JCAPN.pdf

12. The Williams Institute: "The LGBT Divide: A Data Portrait of LGBT People in the Midwestern, Mountain, and Southern States" (2014). See: http://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-divide-Dec-2014.pdf

13. National Coalition of Antiviolence Programs: "Lesbian, Gay, Bisexual, Transgender, and HIV-Affected Hate Violence in 2013" (2014). See: http://www.avp.org/storage/documents/2013_ncavp_hvreport_final.pdf

14. National Center for Injury Prevention and Control of the Centers for Disease Control and Prevention: "The National Intimate Partner and Sexual Violence Survey: 2010 Findings on Victims by Sexual Orientation" (2013). See: http://www.cdc.gov/violenceprevention/pdf/nisvs_sofindings.pdf

15. Centers for Disease Control and Prevention: "MMRW: Sexual identity, sex of sexual contacts, and health-risk behaviors among students in grades 9-12—Youth Risk Behavior Surveillance, selected sites, United States, 2001-2009" (2011). See: http://www.lgbtdata.com/uploads/1/0/8/8/10884149/mmwr_sexual_identity_sex_of_sexual_contacts_yrbs.pdf

16. Gallup: "In U.S., LGBT More Likely Than Non-LGBT to Be Uninsured" (2014). See: http://www.gallup.com/poll/175445/lgbt-likely-non-lgbt-uninsured.aspx

17. Center for American Progress "Moving the Needle: The Impact of the Affordable Care Act on LGBT Communities" (2014). See: https://www.americanprogress.org/issues/lgbt/report/2014/11/17/101575/moving-the-needle/

18. The Henry J. Kaiser Family Foundation: "Health and Access to Care and Coverage for Lesbian, Gay, Bisexual, and Transgender Individuals in the U.S." (2014). See: http://kff.org/disparities-policy/issue-brief/health-and-access-to-care-and-coverage-for-lesbian-gay-bisexual-and-transgender-individuals-in-the-u-s/

19. The Foundation Center: "Key Facts on U.S. Foundations: 2013 edition" (2014). See http://foundationcenter.org/gainknowledge/research/keyfacts2013/foundation-focus.html.

20. Funders Concerned About AIDS: "Philanthropic Support to Address HIV/AIDS in 2013" (2014). See http://www.fcaaids.org/AIDSFunding/ResourceTrackingReport/tabid/305/Default.aspx.

METHODOLOGY

This report combines LGBTQ funding data captured for the *2013 Tracking Report: Lesbian, Gay, Bisexual, Transgender and Queer Grantmaking* by U.S. Foundations; the *2012 Tracking Report: Lesbian, Gay, Bisexual, Transgender and Queer Grantmaking* by U.S. Foundations; and *Lesbian, Gay, Bisexual, Transgender and Queer Grantmaking* by U.S. Foundations – Calendar Year '11. For these reports, requests for grant information were sent to nearly 700 grantmakers. All types of foundations were surveyed - private, public, community, and corporate - as well as nonprofit organizations with grantmaking programs. Information was obtained predominantly through self-reporting by grantmakers, as well as a review of 990s and annual reports.

This report specifically focuses on funding for LGBTQ health issues in the United States and captures grants made to support organizations as well as programs and projects.

The data does not include health grants to organizations or projects that are generally inclusive of LGBTQ populations unless they explicitly target LGBTQ communities or address an LGBTQ health issue. For example, a grant awarded to a local community center to support a breast cancer awareness campaign, open and welcoming to lesbians, would not have been included in the data. If that same center was funded to launch a breast cancer awareness campaign specifically targeting lesbians, then the grant would have been included.

Re-granting dollars are included in charts that rank individual grantmakers to accurately show the overall level of LGBTQ funding provided by each grantmaker. As a result, the charts that rank grantmakers "double-count" re-granting when aggregated. However, for all other tabulations and charts, we have not included dollars awarded for the purpose of re-granting, so as to avoid double counting.

ACKNOWLEDGEMENTS

Thank you to the Robert Wood Johnson Foundation, whose support made this report possible.

Many thanks to our LGBT Health Funding Summit Planning Committee, who guided the development of this report and provided helpful feedback on early drafts. We would also like to acknowledge member and long-time board member Andrew Lane, who also provided helpful feedback and guidance. Finally, many thanks to John Barnes and Sarah Hamilton of Funders Concerned About AIDS, who have been invaluable partners in the development of this report and in so much of our work on LGBTQ health issues.

LGBT HEALTH FUNDING SUMMIT PLANNING COMMITTEE

MISSION

Funders for LGBTQ Issues works to mobilize the philanthropic resources that enhance the well-being of lesbian, gay, bisexual, transgender and queer communities, promote equity and advance racial, economic and gender justice.

BOARD OF DIRECTORS

STAFF

REPORT CREDITS

Authors:
Justin Brown & Ben Francisco Maulbeck

Editors:
Naa Hammond & Kristina Wertz

Creative Director:
Lyle Matthew Kan

Graphic Designer:
Knol Aust

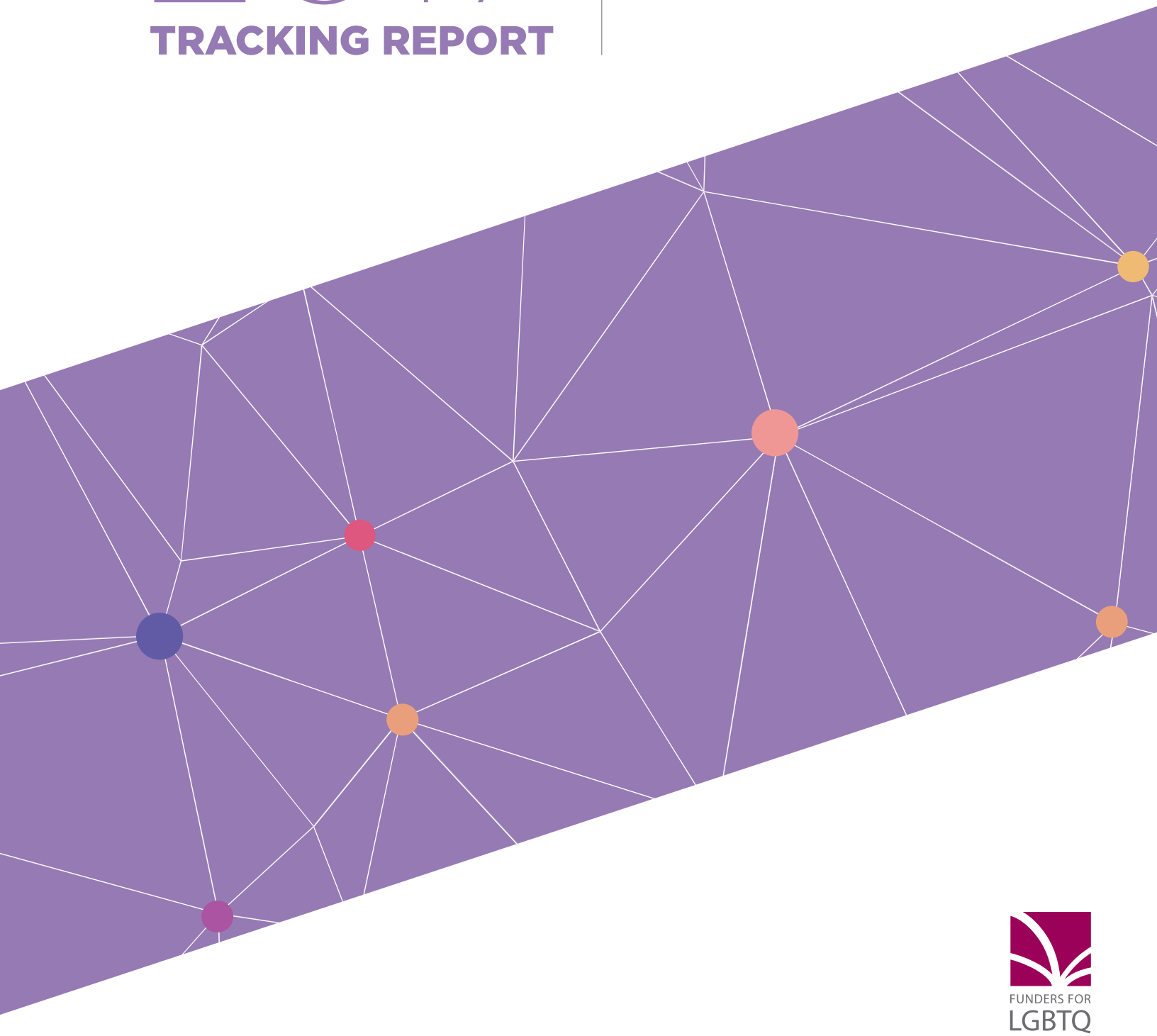
FUNDERS FOR
LGBTQ
ISSUES

104 West 29th Street, 4th Floor
New York, NY 10001
Telephone: 212.475.2930
Fax: 212.475.2532

lgbtfunders.org
@lgbtfunders
facebook.com/LGBTQFunders

2017 TRACKING REPORT

LGBTQ Grantmaking by U.S. Foundations



FUNDERS FOR LGBTQ ISSUES

341 Foundations and Corporations Invested in LGBTQ Issues

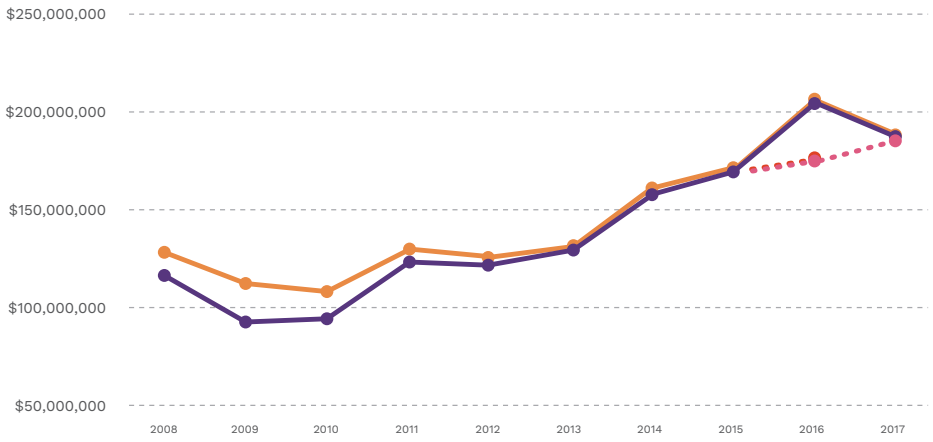
6,297 Grants

$185,841,930 Total Investment in LGBTQ issues

2,247 Grantees

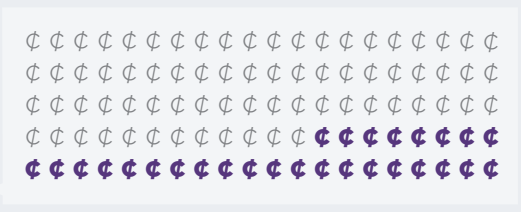
Total Annual LGBTQ Grant Dollars, 2008-2017

Foundation funding for LGBTQ issues totaled $185.8 million in 2017. While this represents a significant decrease of nearly $17 million, or 8 percent, from the $202.3 million in LGBTQ funding reported in 2016, this decline is almost entirely attributable to the philanthropic response to the Pulse Nightclub Massacre. **If we compare annual funding excluding OneOrlando Fund distributions, funding for LGBTQ increased by $10.8 million, or 6 percent.**



	Nominal dollars (not adjusted)	2017 dollars (adjusted for inflation)
		Total without OneOrlando grantmaking (not adjusted)
		Total without OneOrlando grantmaking (adjusted for inflation)
2008	$116,181,019	$132,270,760
2009	$96,533,298	$110,294,457
2010	$96,829,756	$108,847,772
2011	$123,012,423	$134,048,809
2012	$121,412,490	$129,622,854
2013	$129,112,119	$135,853,237
2014	$153,248,693	$158,675,992
2015	$160,702,984	$166,197,005
2016	$202,312,772	$206,621,890
2016 (without One-Orlando grantmaking)	$172,802,772	$176,483,348
2017	$185,841,930	$185,841,930
2017 (without One-Orlando grantmaking)	$183,625,213	$183,625,213

*Inflation numbers are based on the Bureau of Labor Statistics Consumer Price Index.



For every $100 dollars awarded by U.S. foundations, **28 cents specifically supported LGBTQ issues.**

Top 10 Funders of LGBTQ Issues, by Total Dollar Amount

In 2017, **the top ten funders of LGBTQ issues awarded $86.2 million, accounting for 43 percent of all funding** for LGBTQ issues from U.S.-based foundations. Excluding funding awarded in response to the 2016 Pulse Nightclub Massacre, funding from the top ten funders increased by $1.2 million from 2016.

Arcus Foundation	Ford Foundation	Gilead Sciences	Gill Foundation	Open Society Foundations	Tides Foundation	Astraea Lesbian Foundation for Justice	Evelyn and Walter Haas, Jr. Fund	Elton John AIDS Foundation	M.A.C. AIDS Fund
$17.0M	$12.4M	$11.7M	$9.5M	$7.8M	$7.6M	$5.2M	$5.0M	$5.0M	$4.9M

Sources of LGBTQ Grant Dollars, by Funder Type*

While foundation giving to LGBTQ issues (not including OneOrlando Fund) increased in 2017, this growth was not uniform across foundation types. Community foundations and corporate funders had the biggest increases in 2017.

- **8%** Anonymous Funders — $15,570,000
- **6%** Community Foundations — $12,351,847
- **14%** Corporate Funders — $27,099,318
- **22%** LGBTQ Private Foundations — $42,478,374
- **26%** Non-LGBTQ Private Foundations — $50,985,257
- **10%** LGBTQ Public Foundations — $20,254,837
- **14%** Non-LGBTQ Public Foundations — $28,083,033

Distribution of LGBTQ Grant Dollars, by Geographic Focus*

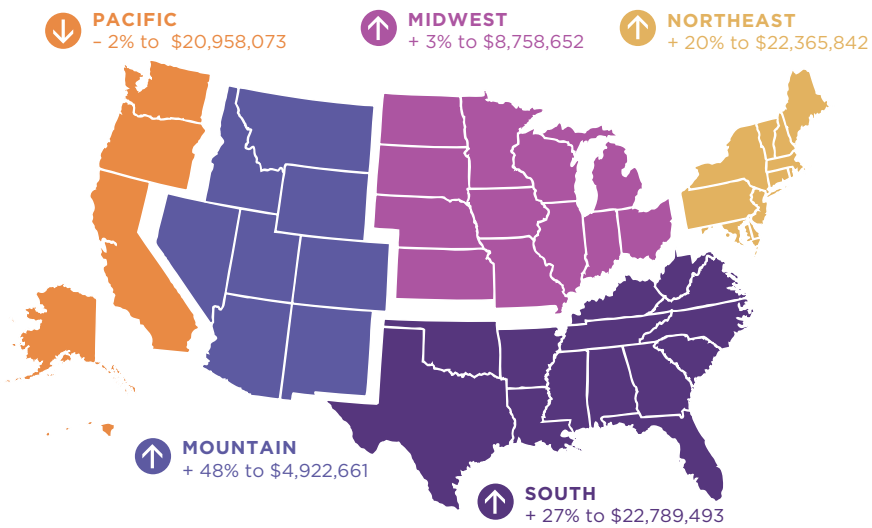
In 2017, approximately 73 percent of funding focused on LGBTQ communities in the United States, while approximately 26 percent focused on LGBTQ issues globally or outside the United States, excluding funding from OneOrlando.

- International (Global Focus) **$14,585,136**
- Outside the U.S. **$33,966,833**
- U.S. - National **$53,106,270**
- U.S. - Regional (Multi-State) **$9,245,146**
- U.S. - Statewide **$18,010,044**
- U.S. - Local **$54,726,476**

These sections exclude funding distributed by the OneOrlando Fund in 2017.

Local, State, and Regional Funding of LGBTQ Issues, by Regional Percentage Change

While the South received the largest share of grant dollars for the first time since we began tracking funding by region, with an increase of 27 percent, the region still receives less funding per LGBTQ adult than the Northeast and Pacific regions.



Notable Changes in 2017

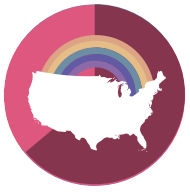
Funding for Trans Communities

2017 $22,564,755
2016 $16,976,892

+33%

Funding for trans communities in the United States continued to increase, reaching a record high of $22,564,755 in 2017 — a 33 percent increase from 2016.

Funding for LGBTQ Organizations



64%

The percentage of funding for domestic LGBTQ organizations decreased relative to funding to non-LGBTQ organizations, accounting for less than two-thirds of domestic funding.

INTRODUCTION

I am pleased to share with you the *2017 Tracking Report: Lesbian, Gay, Bisexual, Transgender, and Queer Grantmaking by U.S. Foundations*. This report captures foundation funding at a complicated moment, a year after we reported on the unprecedented philanthropic response to the Pulse Nightclub Massacre that propelled philanthropic support for LGBTQ issues to the highest level ever recorded, surpassing the $200-million mark for the first time.

In 2017, 341 foundations awarded 6,297 grants totaling $185.8 million in support of organizations and programs addressing lesbian, gay, bisexual, transgender, and queer issues. As expected, the more than $30 million in funds distributed in direct response to Pulse was highly focused in both scope and timing. In 2016, the OneOrlando Fund awarded about $30 million in direct support for approximately 300 survivors and families of victims of the massacre, and in 2017 the OneOrlando Fund gave out its remaining and final disbursements of $2.1 million. **Despite the overall decrease, excluding OneOrlando Fund grantmaking in 2016 and 2017, funding for LGBTQ issues by U.S. foundations actually increased by $10.8 million.** Given the extraordinary nature of the giving of the OneOrlando Fund, and for consistency with the 2016 report, this year's report again presents data both including and excluding OneOrlando Fund funding, particularly in those cases where OneOrlando makes up a disproportionately large amount of a particular sub-category of funding.

Given the changing funding landscape and that several key funders have scaled back support of LGBTQ issues, it is remarkable that funding increased by six percent in 2017. It is also encouraging that funding for LGBTQ issues in the South and for transgender communities reached record-breaking highs in 2017.

As always, the picture painted by the *2017 Tracking Report* is a mixed one. For the second year in a row, the percentage of funding for domestic LGBTQ organizations decreased relative to funding to non-LGBTQ organizations, accounting for less than two-thirds of domestic funding for the first time since we began tracking funding by organization type.

This year's report also sees significant shifts in both leading funders and leading grantees. Gilead Sciences climbed to the number three funder spot, awarding more than $11 million for LGBTQ communities. Funders such as Tides and The California Endowment also saw sharp increases. On the grantee side, the top three recipients were the New York LGBT Center, the Human Rights Campaign Foundation, and African Men for Sexual Health and Rights — none of which were among the top 15 recipients in 2016. As committed and new LGBTQ funders work to respond to a challenging and complex climate both in the U.S. and abroad, diligent tracking of trends and gaps in LGBTQ funding is more important than ever.

As a caveat, remember that this report only includes funding from foundations and corporations — not from individual donors or government agencies — and as such only captures a portion of all giving to LGBTQ issues. Note that the global section of this year's report once again only provides a brief summary, since we provide more detailed information on funding for LGBTQ issues internationally and outside the U.S. in our Global Resources Report, our biennial report series produced in collaboration with the Global Philanthropy Project.

It is my hope that this report continues to prove useful to funders, nonprofit leaders, and other stakeholders in identifying trends, gaps, and opportunities for LGBTQ grantmaking. As with all of our research, our goal is to provide accurate and user-friendly data on LGBTQ funding, so as to advance our mission of increasing the scale and impact of LGBTQ philanthropy.

Take Care,

Ben Francisco Maulbeck
President, Funders for LGBTQ Issues

CONTENTS

OVERVIEW

In 2017, United States-based foundations and corporations awarded 6,297 grants totaling $185.8 million in support for organizations and programs addressing lesbian, gay, bisexual, transgender, and queer issues. While this represents a significant decrease of nearly $17 million, or 8 percent from the $202.3 million in LGBTQ funding reported in 2016, this decline is almost entirely attributable to the philanthropic response to the Pulse Nightclub Massacre. In the aftermath of the most deadly and violent attack on our community in history, nearly $30 million dollars in direct support was distributed to survivors and the families of the victims through the OneOrlando Fund. As anticipated, this funding was highly focused in both scope and timing. In 2017, the OneOrlando Fund awarded a small fraction of what it awarded in 2016, with a second and final round of distributions to the survivors and families of the victims totalling $2.1 million. **If we compare annual funding excluding OneOrlando Fund distributions, funding for LGBTQ increased by $10.5 million, or 6 percent.** This rate of growth is similar to the growth we have reported in previous years.

In the *2016 Tracking Report*, we often reported two funding totals — one inclusive of OneOrlando Fund grantmaking and one excluding OneOrlando Fund grantmaking. For this Tracking Report, we have gone back to a single funding total, noting where necessary how OneOrlando Fund grantmaking significantly impacted a specific category (e.g., in local and statewide funding totals for the state of Florida).

The growth in funding that excludes OneOrlando Fund grantmaking was driven by several major funders significantly increasing their LGBTQ grantmaking. In particular, Gilead Sciences increased its LGBTQ funding by more than 50 percent — awarding a total of $11.7 million and rising to become the number three funder of LGBTQ issues. Several other corporate funders — ViiV Healthcare, Wells Fargo, and Google — all increased their LGBTQ funding by $1 million or more, buoying an overall increase in corporate funding.

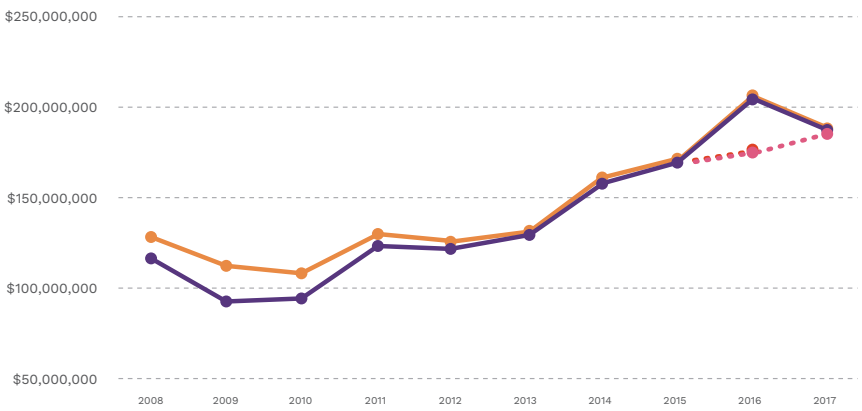
Several leading funders of LGBTQ issues also saw large increases in their LGBTQ funding. In particular, Foundation for a Just Society nearly doubled its LGBTQ grantmaking to $4.6 million. The California Endowment increased its LGBTQ funding by 73 percent, to nearly $3.8 million. Alphawood more than tripled its LGBTQ funding, exceeding $1.6 million and joining the top 20 funders of LGBTQ issues.

LGBTQ funding from mainstream community foundations grew by $5.5 million, an 80 percent increase buoyed in particular by $2.7 million in giving from the California Community Foundation. Several public foundations and intermediaries also saw increases in their LGBTQ funding in 2017, particularly Tides, Astraea Lesbian Foundation for Justice, and Borealis Philanthropy.

On the other hand, eight major LGBTQ funders decreased their support by $500,000 or more — for a total decrease in resources of more than $22 million. Without these losses, the net increase in LGBTQ funding would have been much higher. For several years, the list of top LGBTQ funders was fairly consistent from year to year, but it is now in a period of significant flux, with some funders scaling back support while others increase funding — and with new funders joining the movement to strengthen LGBTQ communities.

Total Annual LGBTQ Grant Dollars, 2008-2017

Not counting funding related to the 2016 Pulse nightclub tragedy, foundation funding for LGBTQ issues totaled $183.7 million in 2017, at a modest rate of growth of 6 percent.



	Nominal dollars (not adjusted)	2017 dollars (adjusted for inflation)
2008	$116,181,019	$132,270,760
2009	$96,533,298	$110,294,457
2010	$96,829,756	$108,847,772
2011	$123,012,423	$134,048,809
2012	$121,412,490	$129,622,854
2013	$129,112,119	$135,853,237
2014	$153,248,693	$158,675,992
2015	$160,702,984	$166,197,005
2016	$202,312,772	$206,621,890
2016 (without One-Orlando grantmaking)	$172,802,772	$176,483,348
2017	$185,841,930	$185,841,930
2017 (without One-Orlando grantmaking)	$183,625,213	$183,625,213

**Inflation numbers are based on the Bureau of Labor Statistics Consumer Price Index.*

TOP GRANTMAKERS

In 2017, the top ten funders of LGBTQ issues awarded nearly $86.2 million, accounting for 43 percent of all funding for LGBTQ issues from U.S.-based foundations. While this does represent a decrease of $48.3 million from 2016, if we exclude the nearly $40 million[1] in funding directly attributed to the 2016 Pulse Nightclub massacre reported in 2016 — funding from the top ten funders increased slightly, by $1.2 million from 2016.

The top twenty funders awarded $117 million, accounting for 59 percent of the year's total. Seven of the top twenty foundations were LGBTQ-specific funders, down from nine in 2016. In 2017, the top twenty list was comprised of six public foundations, ten private foundations, and four corporate funders.

TOP 20 FUNDERS OF LGBTQ ISSUES, BY TOTAL DOLLAR AMOUNT[2,3]

1 **Arcus Foundation**
$17,006,755
New York, NY

2 **Ford Foundation**
$12,445,000
New York, NY

3 **Gilead Sciences**
$11,730,648
Foster City, CA

4 **Gill Foundation**
$9,520,007
Denver, CO

5 **Open Society Foundations**
$7,769,598
New York, NY

6 **Tides Foundation**
$7,596,762
San Francisco, CA

7 **Astraea Lesbian Foundation for Justice**
$5,168,495
New York, NY

8 **Evelyn and Walter Haas Jr. Fund**
$5,038,200
San Francisco, CA

9 **Elton John AIDS Foundation**
$4,966,500
New York, NY

10 **M.A.C. AIDS Fund**
$4,963,389
New York, NY

11 **Foundation for a Just Society**
$4,640,000
New York, NY

12 **H. van Ameringen Foundation**
$4,349,500
New York, NY

13 **The California Endowment**
$3,780,111
New York, NY

14 **Wells Fargo**
$3,339,971
San Francisco, CA

15 **Borealis Philanthropy**
$3,181,800
Minneapolis, MN

16 **ViiV Healthcare**
$2,982,325
Research Triangle Park, NC

17 **California Community Foundation**
$2,778,807
Los Angeles, CA

18 **Strengthen Orlando — OneOrlando Fund**
$2,106,526
Orlando, FL

19 **American Jewish World Service**
$1,984,369
New York, NY

20 **Alphawood Foundation**
$1,686,500
Chicago, IL

TOP 10 FUNDERS OF LGBTQ ISSUES, BY NUMBER OF GRANTS

1	**Pride Foundation** Seattle, WA	348
2	**Horizons Foundation** San Francisco, CA	324
2	**Strengthen Orlando - OneOrlando Fund** Orlando, FL	302
4	**Astraea Lesbian Foundation for Justice** New York, NY	246
5	**Our Fund** Wilton Manors, FL	241
6	**Tides Foundation** San Francisco, CA	180
7	**Borealis Philanthropy** New York, NY	172
8	**Wells Fargo** San Francisco, CA	161
8	**Trans Justice Funding Project** New York, NY	154
10	**Arcus Foundation** New York, NY	147

[1] This $40 million total includes $29,510,000 in funding awarded through the OneOrlando fund as well as $9,445,045 awarded through the Equality Florida Institute in direct response to the Pulse Nightclub tragedy in 2016.

[2] In contrast to other sections of this report, this list of top funders includes dollars awarded for re-granting, so as to capture the full amount of funding flowing from (or through) each funder.

[3] In 2017, anonymous funders awarded a total of $15,570,000. If these anonymous funders appeared in the top twenty list as a single funder, they would rank as the number two U.S.-based foundation funder of LGBTQ issues.

TOP GRANT RECIPIENTS

In 2017, the top 20 recipients of LGBTQ funding received a total of $40.4 million, accounting for 22 percent of all LGBTQ dollars granted in 2017.

Nineteen of the top 20 grantees in 2017 are nonprofit organizations focused specifically on LGBTQ issues. The Southern AIDS Coalition, an advocacy coalition committed fighting AIDS in the U.S. South, was funded for work related to HIV/AIDS in the LGBTQ community. Eighteen of the 20 grant receipts are headquartered in the United States, with seven in California, five in New York City, and three in Washington, DC. Two top grantees are based outside the United States - AMSHER in South Africa and ISDAO in Kenya.

TOP 20 GRANTEES OF FOUNDATION FUNDING FOR LGBTQ ISSUES (EXCLUDES GRANT DOLLARS INTENDED FOR RE-GRANTING)[4]

1. **New York LGBT Center**
   $3,465,902
   New York, NY
2. **Human Rights Campaign (HRC)**
   $3,140,026
   Washington, DC
3. **African Men for Sexual Health and Rights (AMSHER)**
   $3,000,000
   Johannesburg, South Africa
4. **Transgender Law Center**
   $2,868,351
   Oakland, CA
5. **Genders & Sexualities Alliance Network**
   $2,848,955
   Oakland, CA
6. **All Out**
   $2,630,000
   New York, NY
7. **Astraea Lesbian Foundation for Justice**
   $2,200,505
   New York, NY
8. **University of California Los Angeles (UCLA) - Williams Institute**
   $1,926,400
   Los Angeles, CA
9. **Southern AIDS Coalition**
   $1,816,219
   Atlanta, GA
10. **Funders for LGBTQ Issues**
    $1,775,500
    New York, NY
11. **National Center for Lesbian Rights (NCLR)**
    $1,721,788
    San Francisco, CA
12. **Equality California Institute**
    $1,639,850
    Los Angeles, CA
13. **Los Angeles LGBT Center**
    $1,601,192
    Los Angeles, CA
14. **Initiative Sankofa d'Afrique de l'Ouest (ISDAO)**
    $1,500,000
    Nairobi, Kenya
15. **Equality Federation Institute**
    $1,443,500
    Portland, OR
16. **Movement Advancement Project (MAP)**
    $1,430,750
    Denver, CO
17. **LGBTQ Victory Institute**
    $1,397,612
    Washington, DC
18. **New York City Anti-Violence Project (AVP)**
    $1,372,000
    New York, NY
19. **Lambda Legal Defense & Education Fund**
    $1,371,655
    New York, NY
20. **National LGBTQ Task Force**
    $1,320,510
    Washington, DC

[4] In 2017, multiple anonymous grantees received a total of $6,414,363. This total includes individuals who received direct financial support in the form of scholarships or other direct financial assistance. If these anonymous grantees were to appear as a single entity on the top twenty list they would rank as the number one grant recipient of LGBTQ Funding.

SPECIAL UPDATE

THE PHILANTHROPIC RESPONSE TO THE PULSE TRAGEDY

On June 12, 2016, a gunman attacked the Pulse Nightclub, a gay club in Orlando, Florida, taking 49 lives, wounding 68 others, and forever changing the lives of countless more. It was Latin night, and the majority of victims and survivors were LGBTQ and Latinx.

More than $30 million was raised in response to the tragedy, the largest fundraising effort in history for a cause related to LGBTQ communities. Last year's 2016 Tracking Report provided a detailed report on the various philanthropic and government initiatives deployed in the aftermath of the tragedy. That year, the **OneOrlando Fund** provided $29.5 million in direct financial support for approximately 300 hundred survivors and families of victims of the shooting. This direct assistance was tightly focused in both scope and time, but constituted a full 15 percent of the year's total LGBTQ funding. As such, at several places in last year's report, we showed funding data both including and excluding OneOrlando Fund funding, so as to offer figures that were inclusive of the full scope of the year's giving but also that showed trends and comparisons with giving from other years.

While the vast majority of dollars related to the Pulse tragedy were given out in 2016, the philanthropic response continued in 2017 and beyond. The OneOrlando Fund distributed an additional $2 million to survivors and families of victims. For consistency with last year's report, this year's report shows figures both including and excluding OneOrlando Fund distributions in those cases where they make up a disproportionate share of a specific subcategory of funding.

Several other philanthropic initiatives awarded funding in 2017, particularly those seeking to address the long-term effects of the shooting — and the long-standing inequities that the tragedy brought to light. **The Better Together Fund** of the **Central Florida Foundation** awarded $406,054 for mental health and other social services, and to foster increased awareness and understanding across differences. **The Contigo Fund**, housed at **OurFund Foundation**, provided $614,824 for efforts to heal, educate and empower communities most affected by the tragedy and build bridges connecting all of Central Florida's diverse community groups.

The continuing needs and ongoing philanthropic efforts in response to the Pulse massacre are a demonstration of the long-term nature of the challenges presented by disasters and mass tragedies. While the bulk of funding related to Pulse was raised and awarded in the first six months of the tragedy, the philanthropic work in Central Florida's LGBTQ and Latinx communities carries on — with fewer resources but also with potential not only for healing but for fostering lasting change.

SOURCES OF LGBTQ FUNDING

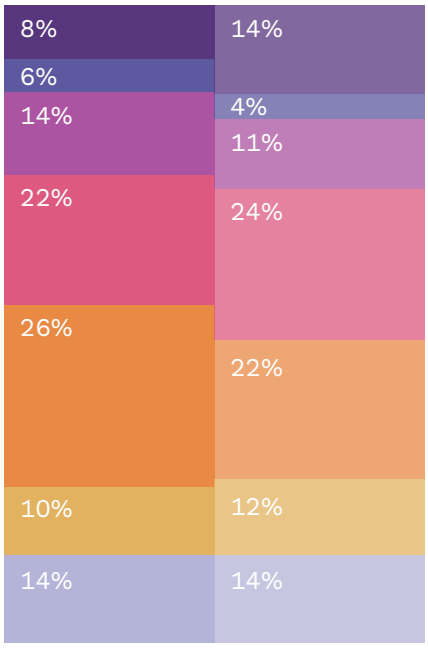
While foundation giving to LGBTQ issues (exclusive of OneOrlando Fund grantmaking) increased in 2017, this growth was not uniform across foundation types, and some foundation categories decreased their LGBTQ grant making in 2017.

Community Foundation giving saw the greatest increase, nearly doubling between 2016 and 2017 to account for 6 percent of all funding in 2017. This increase reflects the greater representation of community foundations in this report as well as significant growth in donor advised giving for LGBTQ issues reported at several institutions.

Corporate funding for LGBTQ issues also increased by $6.6 million, or 33 percent, to account for 14 percent of all giving in 2017. This rise was driven by substantial increases from Gilead Sciences and ViiV Healthcare for HIV/AIDS work in LGBTQ communities.

Anonymous foundations decreased funding by over 40 percent from a high of over $27 million in 2016 when anonymous foundations accounted for 11 percent of funding for LGBTQ Issues. Excluding funding from the OneOrlando Fund, the LGBTQ public foundations also decreased, falling by $4 million from 2016 to a three year low of $20.2 million, or 10 percent of funding for LGBTQ issues. This is due in large part to the end of the Weiland Bequest giving, which was administered by Pride Foundation. Giving from the Weiland Bequest typically accounted for $4-$5 million a year for the last eight years.

Sources of LGBTQ Grant Dollars by Funder Type[5]



	2017	2016
Anonymous Funders	$15,570,000	$27,013,706
	8%	14%
Community Foundations	$12,351,847	$6,853,988
	6%	4%
Corporate Funders	$27,099,318	$20,449,310
	14%	11%
LGBTQ Private Foundations	$42,478,374	$41,817,405
	22%	22%
Non-LGBTQ Private Foundations	$50,985,257	$46,582,150
	26%	24%
LGBTQ Public Foundations	$20,254,837	$24,146,411
	10%	12%
	$20,144,646 (including OneOrlando Fund)	$33,591,456 (including OneOrlando Fund)
Non-LGBTQ Public Foundations	$28,083,033	$27,410,044
	14%	14%
	$30,189,559 (including OneOrlando Fund)	$56,920,044 (including OneOrlando Fund)
Total	$196,822,666	$194,273,013
	$198,929,192 (including OneOrlando Fund)	$202,212,772 (including OneOrlando Fund)

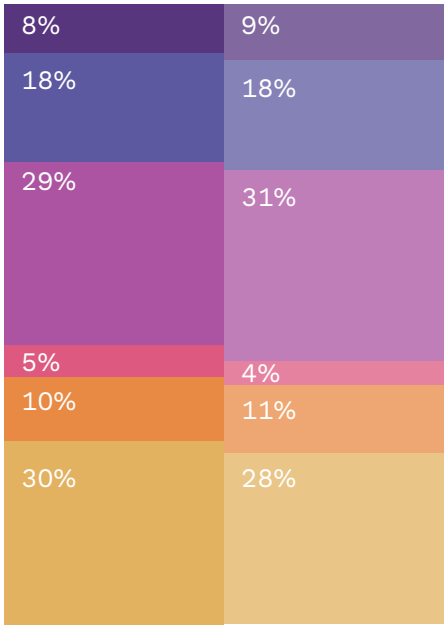
[5] In contrast to other sections of this report, this chart includes dollars awarded for re-granting, so as to capture the full amount of funding flowing from (or through) each type of funder.

GEOGRAPHIC FOCUS

In 2017, approximately 73 percent of funding focused on LGBTQ communities in the United States while approximately 26 percent focused on LGBTQ issues globally, or outside the United States.

Funding for LGBTQ communities in the United States totaled $134.8 million in 2017. The majority of the domestic funding focused on work at the local level — totaling $54.7 million, an increase of 14 percent from the $47.5 million reported in 2016, and accounting for 30 percent of all funding in 2017. Funding for work that was national in scope decreased by more than $500,000 but accounted for a similarly large share of domestic funding at 29 percent. Support for work at the state and regional level also remained relatively consistent in their share of funding, accounting for 10 and 5 percent of all funding, respectively.

Distribution of LGBTQ Grant Dollars by Geographic Focus



	2017	2016
International (Global Focus)	$14,585,136	$14,696,231
	8%	9%
Outside the U.S.	$33,966,833	$30,816,851
	18%	18%
U.S. — National	$53,106,270	$53,884,827
	29%	31%
U.S. — Regional (Multi-State)	$9,245,146	$6,060,245
	5%	4%
U.S. — Statewide	$18,010,044	$19,808,569
	10%	11%
U.S. — Local	$54,726,476	$47,536,049
	30%	28%
	$56,833,002 (including OneOrlando Fund)	$77,046,049 (including OneOrlando Fund)
Total	$183,350,213	$172,802,772
	$185,841,930 (including OneOrlando Fund)	$202,212,772 (including OneOrlando Fund)

TYPE OF SUPPORT

Consistent with established trends, funding for program or project specific support was the most common type of support in 2017, decreasing by 3 percent from 2016 but still accounting for 46 percent of all funding.

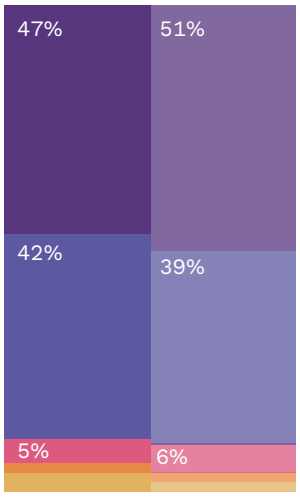
Funding for general operating support increased by 14 percent or nearly $10 million dollars to account for 42 percent of all funding, a record for this category.

Funding for direct victim support decreased substantially as distributions from the OneOrlando Fund to survivors and families of victims of the Pulse Nightclub tragedy were mostly disbursed in 2016.

Funding for capacity building remained level while scholarship and fellowship support declined slightly.

The 'other' category captures other types of funding, including: capital support, corporate matching gifts, emergency funding, endowment support, matching grants, prizes and awards, seed funding, sponsorships, as well as funds awarded to international intermediaries for the the purposes of regranting.

Distribution of LGBTQ Grant Dollars by Type of Support



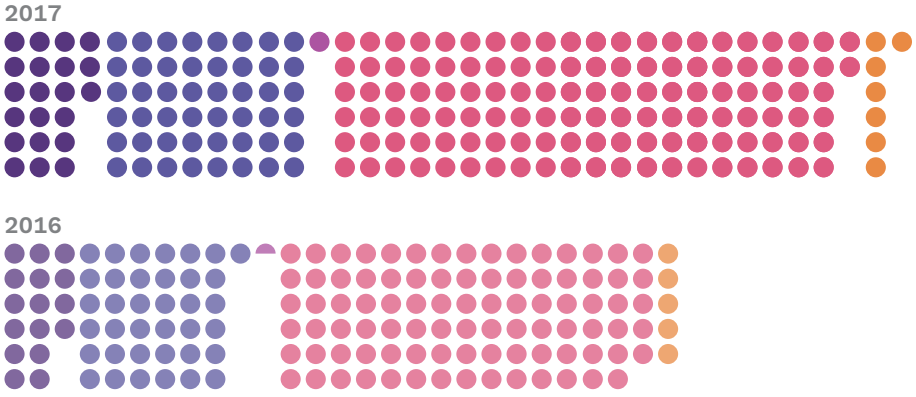
	2017	2016
Program/Project Support	$86,062,643	$88,073,569
	47%	51%
General Operating Support	$76,692,167	$67,003,518
	42%	39%
Direct Victim Support	$0	$0
	<1%	<1%
	$2,106,526 (including OneOrlando Fund)	$29,510,000 (including OneOrlando Fund)
Capacity-Building Support	$9,861,899	$9,628,993
	5%	6%
Scholarships and Fellowships	$3,598,538	$4,078,279
	2%	2%
Other	$7,520,158	$4,078,279
	4%	2%
Total	$183,735,404	$172,702,772
	$185,841,930 (including OneOrlando Fund)	$202,212,772 (including OneOrlando Fund)

POPULATION FOCUS

Consistent with previous reporting, the vast majority of LGBTQ grants in 2017, over $142.6 million or 73% of funding, targeted the LGBTQ community broadly. The data below looks at grants that specifically supported one segment of the LGBTQ community.

Trans funding increased by over 40 percent from a record high of $22.4 million in 2016 to over $32 million on 2017, to account for 17 percent of funding for LGBTQ issues. Funding for lesbians and queer women, bisexuals, and intersex people also saw modest increases in 2017.

Distribution of LGBTQ Grant Dollars by Sexual Orientation, Gender Identity, and Sex Characteristics



	2017	2016
Lesbians/Queer Women	$5,127,585	$4,029,117
	3%	2%
Gay Men/Queer Men/MSM	$11,937,066	$9,126,551
	6%	5%
Bisexual People	$210,776	$300
	<1%	<1%
Transgender People	$32,072,197	$22,434,839
	17%	11%
Intersex People	$1,737,605	$1,362,156
	1%	1%

● = $250,000

STRATEGIES FUNDED

Consistent with previous years, advocacy was again the most funded strategy in 2017, with 42 percent of LGBTQ funding supporting advocacy work.

In 2016, the victim support category was added to capture the nearly $30 million in funding to support the families of victims and survivors of the Pulse Nightclub Massacre in Orlando. In 2017, the OneOrlando Fund awarded an additional $2.1 million in direct victim support to families of victims and survivors.

Detailed Breakdown of Strategies Funded

Strategy	2017 Funding	%	2016 Funding	%
Advocacy	$78,471,664	42%	$77,999,796	39%
Advocacy (General)	$42,945,661	23%	$39,631,010	20%
Community Organizing	$16,094,242	9%	$12,447,844	6%
Intergovernmental Advocacy	$0	<1%	$5,000	<1%
Litigation	$9,189,784	5%	$11,476,421	6%
Public Education	$10,241,977	6%	$14,439,522	7%
Capacity-Building and Training	$22,259,175	12%	$23,429,941	11%
Conferences/Seminars/Travel Grants	$2,233,137	1%	$1,865,648	1%
Leadership Development	$6,054,590	3%	$8,451,762	4%
Organizational Capacity Building	$10,066,003	5%	$8,142,294	4%
Training/Technical Assistance	$3,905,445	2%	$4,970,237	2%
Culture and Media	$11,813,008	6%	$9,607,592	5%
Culture	$8,768,676	5%	$7,363,164	4%
Electronic Media/Online Services	$593,502	<1%	$749,640	<1%
Film/Video/Radio	$2,450,830	1%	$1,494,788	1%
Direct Service	$31,978,458	17%	$30,864,852	15%
Philanthropy and Fundraising	$20,590,368	11%	$14,119,724	7%
Fundraising Event	$1,198,854	1%	$1,166,645	1%
Matching Grant	$25,000	<1%	$10,250	<1%
Philanthropy	$19,366,515	10%	$12,942,830	6%
Research	$11,392,823	6%	$11,155,615	6%
Victim Support	$2,106,526	1%	$29,510,000	15%
Other	$7,430,320	4%	$5,625,252	3%
Multi-Strategy	$6,941,376	4%	$5,118,891	3%
Other	$488,944	<1%	$506,361	<1%
Total	**$185,841,930**		**$202,312,772**	

ISSUES ADDRESSED

Civil and human rights issues continued to receive the largest share of funding in 2017, accounting for nearly half of all LGBTQ funding. Funding for health and wellbeing increased to nearly 20 percent, driven largely by funding for HIV/AIDS.

Funding for issues related to violence, homophobia, and transphobia declined sharply, due to the sharp increase of funding reported in 2016 related to the Pulse Nightclub Massacre in Orlando.

Breakdown of Issues Addressed

Issue	2017 Funding	%	2016 Funding	%
Civil and Human Rights	$85,774,320	46%	$89,502,347	44%
Health and Wellbeing	$35,943,783	19%	$30,985,113	15%
Strengthening Communities, Families, and Visibility	$30,763,787	17%	$28,405,924	14%
Education and Safe Schools	$8,815,516	5%	$6,132,996	3%
Violence, Homophobia, and Transphobia	$6,673,023	4%	$31,900,337	16%
Economic Issues	$6,629,890	4%	$6,216,616	3%
Other Issues	$11,432,022	6%	$9,169,439	5%
Total	**$185,841,930**		**$202,312,772**	

DOMESTIC FUNDING OF LGBTQ ISSUES

In 2017, funding for LGBTQ issues in the United States totaled, $137 million - down slightly from last year's record high of $157.1 million that included nearly $30 million in direct victim support for those affected by the Pulse Nightclub Massacre. With dollars for re-granting included, total domestic funding was $146.5 million in 2017.

Local and statewide funding also dipped slightly for the same reason, totaling $83.9 million. Down from the record high of $102.9 million in 2016, but higher than the $73.4 million in 2016 without OneOrlando Fund grantmaking.

TOP 10 DOMESTIC FUNDERS[6]

1. **Gilead Sciences**
   $10,097,801
   Foster City, CA
2. **Arcus Foundation**
   $9,729,000
   New York, NY
3. **Gill Foundation**
   $9,520,007
   Denver, CO
4. **Evelyn & Walter Haas, Jr. Fund**
   $5,038,200
   San Francisco, CA
5. **Ford Foundation**
   $5,030,000
   New York, NY
6. **H. van Ameringen Foundation**
   $4,319,500
   New York, NY
7. **Elton John AIDS Foundation**
   $4,080,500
   New York, NY
8. **The California Endowment**
   $3,775,111
   Los Angeles, CA
9. **Tides Foundation**
   $3,508,122
   San Francisco, CA
10. **Wells Fargo**
    $3,214,971
    San Francisco, CA

TOP 10 DOMESTIC GRANTEES[7]

1. **New York LGBT Center**
   $3,465,902
   New York, NY
2. **Human Rights Campaign (HRC) Foundation**
   $3,080,026
   Washington, DC
3. **Transgender Law Center**
   $2,868,351
   Oakland, CA
4. **Genders & Sexualities Alliance Network**
   $2,848,955
   Oakland, CA
5. **Southern AIDS Coalition**
   $1,816,219
   Atlanta, GA
6. **Funders for LGBTQ Issues**
   $1,775,500
   New York, NY
7. **National Center for Lesbian Rights (NCLR)**
   $1,721,788
   San Francisco, CA
8. **Equality California Institute**
   $1,639,850
   Los Angeles, CA
9. **Los Angeles LGBT Center**
   $1,601,192
   Los Angeles, CA
10. **Equality Federation Institute**
    $1,443,500
    Portland, OR

[6] In 2017, anonymous funders awarded a total of $9,210,000 to support LGBTQ issues in the United States. If the anonymous funders appeared in the top ten list as a single funder, they would rank as the number four funder of LGBTQ issues domestically.

[7] In 2017, multiple anonymous grantees received a total of $4,901,944 for work benefiting LGBTQ communities in the United States. This includes the individuals who received victim support in the aftermath of the Pulse Nightclub Massacre in Orlando. If the multiple anonymous grantees appeared in the top twenty list as a single grantee, they would rank as the number one grant recipient of domestic LGBTQ funding.

TOP 10 FUNDERS OF LOCAL AND STATE-LEVEL WORK

1 **Gilead Sciences**
$5,646,283
Foster City, CA

2 **Gill Foundation**
$4,276,007
Denver, CO

3 **The California Endowment**
$3,772,111
Los Angeles, CA

4 **Arcus Foundation**
$3,433,000
New York, NY

5 **Elton John AIDS Foundation**
$3,198,000
New York, NY

6 **Tides Foundation**
$2,483,622
San Francisco, CA

7 **H. van Ameringen Foundation**
$2,380,000
New York, NY

8 **Borealis Philanthropy**
$2,357,250
Minneapolis, MN

9 **ViiV Healthcare**
$2,188,732
Research Triangle, NC

10 **Strengthen Orlando — OneOrlando Fund**
$2,106,526
Orlando, FL

TOP 10 LOCAL AND STATE-LEVEL GRANTEES[8]

1 **New York LGBT Center**
$3,465,902
New York, NY

2 **Southern AIDS Coalition**
$1,816,219
Atlanta, GA

3 **Equality California Institute**
$1,639,850
Los Angeles, CA

4 **Los Angeles LGBT Center**
$1,586,192
Los Angeles, CA

5 **Freedom for All Americans**
$1,190,000
Washington, DC

6 **Pride Foundation**
$1,119,638
Seattle, WA

7 **Desert AIDS Project**
$1,084,775
Palm Springs, CA

8 **Hetrick-Martin Institute (HMI)**
$1,017,672
New York, NY

9 **Genders & Sexualities Alliance Network**
$1,009,955
Oakland, CA

10 **Women With A Vision**
$979,559
New Orleans, LA

[8] In 2017, multiple anonymous grantees received a total of $3,598,271 for the benefit of local and state-wide LGBTQ communities. This includes the individuals who received victim support in the aftermath of the Pulse Nightclub Massacre in Orlando. If the multiple anonymous grantees appeared in the top ten list as a single grantee, they would rank as the number one grant recipient of local and state-level funding.

LOCAL, STATE, AND REGIONAL FUNDING OF LGBTQ ISSUES

Funding for local, statewide, and regional LGBTQ work in the United States totaled $84 million in 2017, down for the record high of $102.9 million in 2016. That record high was made possible by the OneOrlando Fund giving. Without OneOrlando Fund grantmaking, the total was $73.4 million 2016 and $81.9 million in 2017.

The South received the largest share of grant dollars for the first time since we began tracking funding by region. The South received $22.7 million in funding — $24.8 million if you include final disbursements from the OneOrlando Fund for the survivors and the families of the victims of the Pulse Nightclub Massacre — representing a 27 percent increase in funding.

The Northwest region received the second largest share of grant dollars with $22.4 million in funding, representing a 20 percent increase in funding. Meanwhile **the Pacific** region saw a 3 percent decrease in funding, with $21 million in 2017. **The Midwest** posted a modest three percent increase with $8.8 million in funding. Meanwhile, **the Mountain** region saw the biggest percentage increase, 48 percent, but received the smallest share of grant dollars at just $4.9 million.

In 2017, funding for **Puerto Rico** increased by 75 percent to $341,644. There was also $1.8 million awarded for local or regional work that cut across regions or was otherwise anonymous.

California and **New York** were once again the top funded states in 2017, at $16.4 million and $15.7 million respectively. This represents a slight dip for California and a record high for New York. With a $4.8 million increase in funding in 2017, New York experienced the most significant increase in local and statewide funding. If you exclude OneOrlando Fund grantmaking, California and New York were the only states to receive more than $5 million in funding. **Florida**, **Georgia**, **Illinois**, and **Texas** all received more than $2.5 million in funding.

In 2017, 28 states saw an increase in local and statewide funding while 22 states and the District of Columbia experienced a decrease. Eighteen states and the District of Columbia received more than $1 million in LGBTQ funding, up from 14 in 2016. No state that received more than $1 million in funding in 2016 dropped below that level. The states joining the "million dollar club" in 2017 included returning states **Colorado** and **Ohio** and first-timers **Arizona** and **New Mexico**.

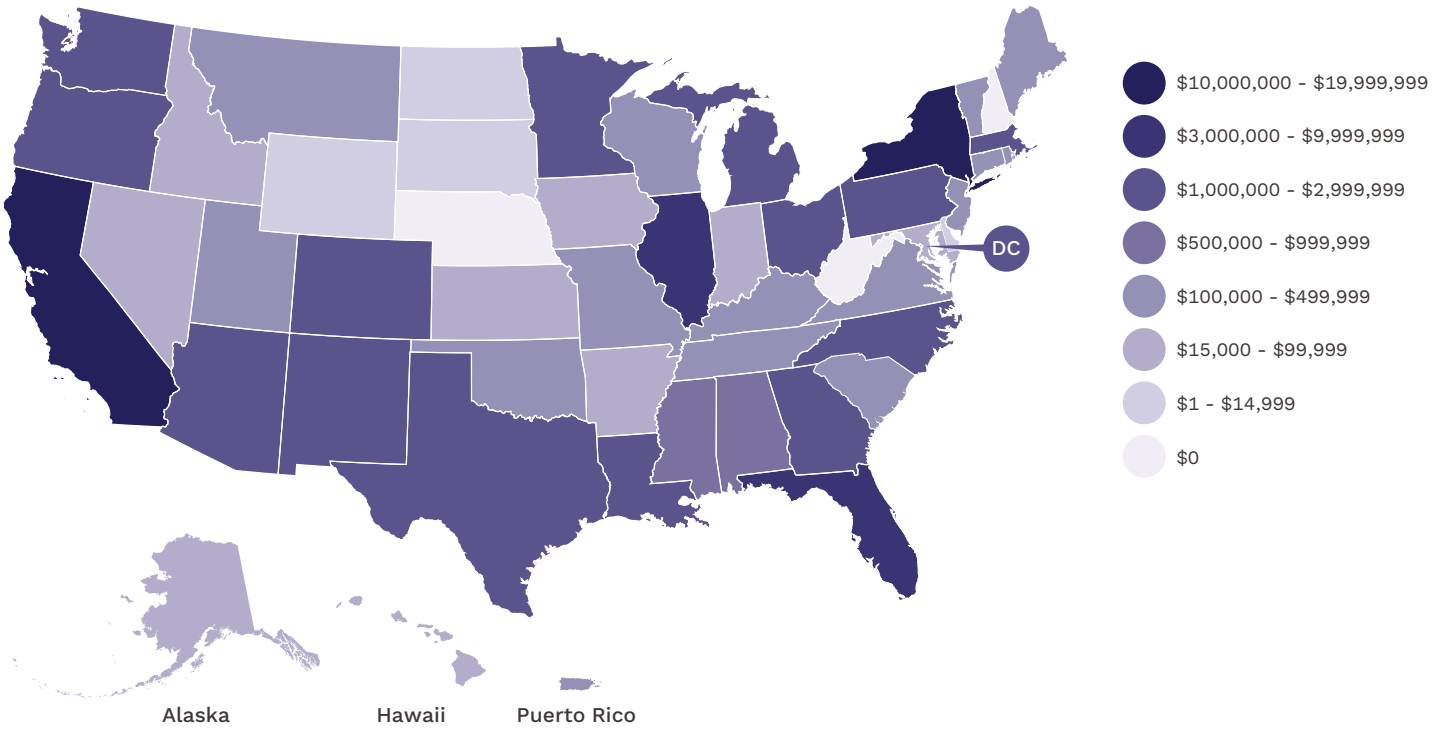
Most of the decreases were moderate, with only 5 states and the District of Columbia seeing decreases of $250,000 or more. **Washington** — the state to experience the biggest decrease in 2017 — was the only state to witness a decrease of more than $500,000.

There were three states where we could not identify any LGBTQ funding in 2017: **Nebraska**, **New Hampshire**, and **West Virginia**.

Local, State, and Regional LGBTQ Funding, By Region

Region	2017	2016	Percent Change
Midwest	$8,758,652	$8,483,928	▲ 3%
Mountain	$4,922,661	$3,321,748	▲ 48%
Northeast	$22,365,842	$18,630,833	▲ 20%
Pacific	$20,958,073	$21,341,571	▼ 2%
South	$22,789,493 ($24,896,019 with OneOrlando Fund Grantmaking)	$17,882,284 ($47,392,284 with OneOrlando Fund Grantmaking)	▲ 27%
U.S. Territories (Puerto Rico)	$341,644	$195,000	▲ 75%
Multi-Region/Unspecified	$1,845,300	$3,548,000	▼ 48%
Total	**$81,981,666 ($84,088,192 with OneOrlando Fund Grantmaking)**	**$73,404,863 ($102,914,863 with OneOrlando Fund Grantmaking)**	**▲ 11%**

Local, State, and Regional Funding of LGBTQ Issues, by State (Density Map)



Midwest	$8,758,652
Illinois	$3,182,681
Indiana	$40,920
Iowa	$22,975
Kansas	$25,000
Michigan	$1,168,242
Minnesota	$1,758,361
Missouri	$349,525
Nebraska	$-
North Dakota	$2,500
Ohio	$1,286,148
South Dakota	$25,800
Wisconsin	$392,000
Midwest Region (General)	$504,500

Mountain	$4,922,661
Arizona	$1,740,003
Colorado	$1,188,375
Idaho	$53,650
Montana	$320,538
Nevada	$19,600
New Mexico	$1,227,050
Utah	$364,945
Wyoming	$8,500
Mountain Region (General)	$10,000

Northeast	$22,365,842
Connecticut	$108,205
Delaware	$10,000
District of Columbia	$1,422,093
Maine	$171,100
Maryland	$858,972
Massachusetts	$1,615,174
New Hampshire	$-
New Jersey	$78,700
New York	$15,739,488
Pennsylvania	$1,088,225
Rhode Island	$249,052
Vermont	$210,458
Northeast Region (General)	$814,375

Pacific	$20,958,073
Alaska	$73,500
California	$16,441,044
Hawaii	$74,666
Oregon	$1,825,265
Washington	$1,105,721
Pacific Region (General)	$1,437,877

U.S. Territories	$341,644
Puerto Rico	$341,644

Multi-Regional / Unspecified	$1,845,300

South (Including OneOrlando Fund)	$24,896,019
South (Not Including OneOrlando Fund)	$22,789,493
Alabama	$624,832
Arkansas	$15,500
Florida*	$4,759,082
Florida (with OneOrlando Fund Grantmaking)	$6,865,608
Georgia	$2,573,326
Kentucky	$185,714
Louisiana	$1,634,888
Mississippi	$696,300
North Carolina	$1,567,957
Oklahoma	$282,729
South Carolina	$380,466
Tennessee	$479,300
Texas	$2,623,766
Virginia	$277,240
West Virginia	$-
South Region (General)	$6,688,394

Total	**$81,981,666**
Total (with OneOrlando Fund Grantmaking)	**$84,088,192**

FUNDING PER LGBT ADULT

Our metric of GDQ, or "Grant Dollars per Queer," analyzes the total local and statewide LGBTQ grant dollars awarded per state or region divided by the estimated number of adults in said state or region who identify as lesbian, gay, bisexual, or transgender. The goal of the GDQ is to assess the level of funding for each state relative to its population.

In 2016, the overall GDQ decreased slightly to $7.36, partially on account of more LGBT adults coming out in the Gallup surveys and a subsequent increase in the estimated number of LGBT adults in the United States.

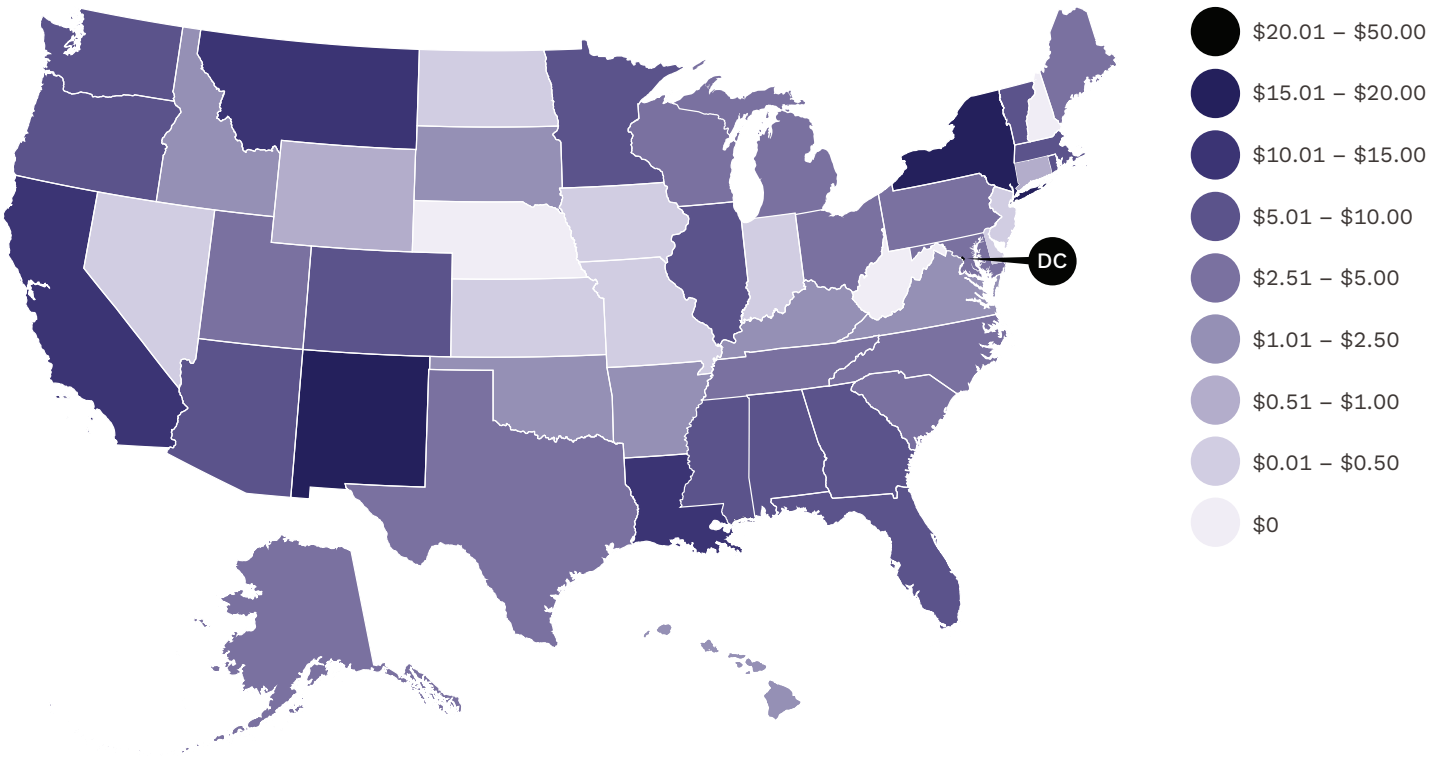
Despite the increase in LGBT adults and the decrease in the overall GDQ, both the average GDQ and the median GDQ increased. In 2017, the average GDQ for states and the District of Columbia was $4.77, up from $4.68 in 2016. In 2017, the median GDQ for the 50 states and the District of Columbia was $3.21, up from $2.92 in 2016.

In 2017, 27 states saw their GDQ increase, while the other 23 states and the District of Columbia witnessed a decrease in GDQ. **New Mexico** had the largest increase, with a $6.79 increase, while the **District of Columbia** had the biggest decrease, with a $11.20 decrease.

The **District of Columbia**, **New York**, and **New Mexico** had the three highest GDQs, in that order. They join **California**, **Louisiana**, and **Montana** as the only six states with GDQ's over $10.

While the South has become the most funded region, it still has a much lower GDQ than the Pacific or Northeast, at $6.25 compared to $9.60 and $9.48, respectively. The Midwest has the lowest GDQ at $4.09. It is the lowest GDQ for any region in last three years.

LGBTQ Funding per LGBT Adult, by State



LGBTQ Funding per LGBT Adult, by State

Midwest	$4.09
Illinois	$7.49
Indiana	$0.18
Iowa	$0.26
Kansas	$0.34
Michigan	$3.73
Minnesota	$9.95
Missouri	$1.94
Nebraska	$–
North Dakota	$0.16
Ohio	$3.29
South Dakota	$1.29
Wisconsin	$2.27

Mountain	$6.06
Arizona	$6.99
Colorado	$5.83
Idaho	$1.47
Montana	$13.27
Nevada	$0.15
New Mexico	$16.90
Utah	$4.43
Wyoming	$0.58

Pacific	$9.60
Alaska	$3.59
California	$10.15
Hawaii	$1.45
Oregon	$9.83
Washington	$3.62

South	$6.25
South (with OneOrlando Fund Grantmaking)	$6.38
Alabama	$5.31
Arkansas	$0.20
Florida	$6.06
Florida (with OneOrlando Fund Grantmaking)	$8.74
Georgia	$7.14
Kentucky	$1.58
Louisiana	$11.76
Mississippi	$8.72
North Carolina	$4.85
Oklahoma	$2.49
South Carolina	$2.73
Tennessee	$2.60
Texas	$3.00
Virginia	$1.07
West Virginia	$–

Northeast	$9.48
Connecticut	$0.98
Delaware	$0.29
District of Columbia	$25.24
Maine	$3.21
Maryland	$4.35
Massachusetts	$5.40
New Hampshire	$–
New Jersey	$0.28
New York	$19.94
Pennsylvania	$2.61
Rhode Island	$6.50
Vermont	$7.93

LGBTQ Funding, by Region

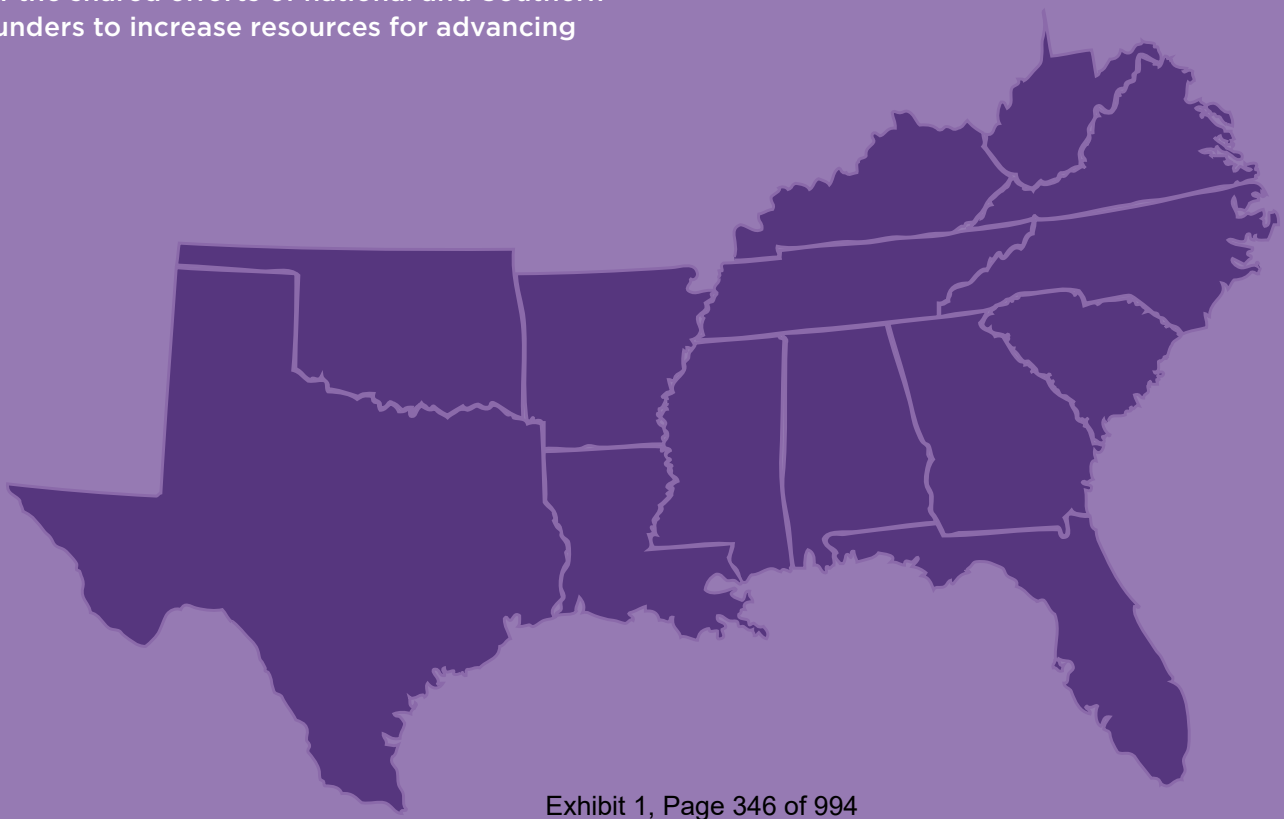
Region	2017	2016	Percent Change
Midwest	$4.09	$4.38	▼ 7%
Mountain	$6.06	$4.64	▲ 31%
Northeast	$9.48	$8.86	▼ 7%
Pacific	$9.60	$10.92	▼ 12%
South	$6.28 ($6.86 with OneOrlando Fund Grantmaking)	$5.64 ($14.96 with OneOrlando Fund Grantmaking)	▲ 11%
Total	**$7.36 ($7.55 with OneOrlando Fund Grantmaking)**	**$7.43 ($10.42 with OneOrlando Fund Grantmaking)**	▼ 1%

SPECIAL UPDATE
GROWTH IN FUNDING FOR LGBTQ ISSUES IN THE SOUTH

In 2017, LGBTQ funding for the South exceeded $22 million (excluding OneOrlando Funding), an increase of 27 percent over 2016. Since we began tracking funding at the regional level and launched our Out in the South Initiative, LGBTQ funding for the South has nearly quintupled. As of this tracking report, the region now receives more LGBTQ funding than any other region in the U.S., followed closely by the Northeast and Pacific. Nevertheless, when accounting for the fact that the South is home to more than one-third of the country's LGBTQ adult population, the region still lags behind the Northeast and the Pacific in LGBTQ funding per LGBT adult.

The growth in Southern LGBTQ funding is the result of the shared efforts of national and Southern funders to increase resources for advancing LGBTQ justice in the region. While this increase in funding is a positive step forward, it is also highly dependent on a small number of funders and spread unevenly across the region. As shown in the section on Local, State, and Regional Funding, only five of fourteen Southern states have surpassed $1 million in LGBTQ funding: Florida, Georgia, Louisiana, North Carolina, and Texas. States such as Arkansas, Kentucky, Oklahoma, Virginia, and West Virginia receive LGBTQ funding ranging from $0 to less than $300,000.

In addition, the increase in funding has been highly dependent on a small number of funders, largely based outside the South.



TOP 10 FUNDERS FOR LGBTQ ISSUES IN THE SOUTH

1	**Gilead Sciences** Foster City, CA	$3,527,697
2	**Elton John AIDS Foundation** New York, NY	$1,974,000
3	**Gill Foundation** Denver, CO	$1,666,007
4	**Arcus Foundation** New York, NY	$1,339,500
5	**Evelyn & Walter Haas, Jr. Fund** San Francisco, CA	$963,833
6	**Astraea Lesbian Foundation for Justice** New York, NY	$840,000
7	**Amy Mandel and Katina Rodis Fund** Asheville, NC	$810,820
8	**Borealis Philanthropy** Minneapolis, MN	$743,250
9	**ViiV Healthcare** Research Triangle, NC	$693,000
10	**Ford Foundation** New York, NY	$600,000

The top 10 funders of LGBTQ issues in the South collectively awarded about half of all funding for the region. Of these funders, only two were based in the South pointing to the need for cultivating locally driven, sustainable resources for the region's LGBTQ movement. Much of the increase in funding was also driven by a rise in HIV funding for LGBTQ funding in the South, driven largely by Gilead Sciences and the Elton John AIDS Foundation. In part, this reflects the philanthropic response to the alarming incidence of HIV in the region, which accounts for half of new HIV infections.

As Funders for LGBTQ Issues and its members continue to advance the work of the Out in the South Initiative, these data indicate both significant progress as well as the need to address the continued under-resourcing of the region's needs.

ISSUES ADDRESSED IN DOMESTIC FUNDING

In the year after the Pulse Nightclub Massacre, Addressing Violence, Homophobia, Biphobia, and Transphobia went from being the second most funded issue area to its normal spot as the least funded issue area.

Civil Rights continued its run as the most funded issue area, but saw no growth in the actual funding. Health and Wellbeing was the second most funded issue area, while Strengthening Communities, Families, and Visibility was the third most funded issue area.

LGBTQ funding focused on education, gender identity rights, HIV/AIDS, religion, religious exemptions, safe schools, sexual and reproductive rights and justice, and visibility increased, with each issue area seeing an increase of $1 million or more.

Detailed Breakdown of Issues Addressed in Domestic Funding

Issue	2017	%	2016	%
Civil Rights	$52,694,352	38%	$55,254,503	35%
Civil Rights (General)	$25,603,813	19%	$32,709,734	21%
Criminalization and Criminal Justice Reform	$4,171,178	3%	$3,686,398	2%
Gender Identity Rights	$9,064,300	6%	$6,310,272	4%
Immigration and Refugee Issues	$2,902,150	2%	$2,844,901	2%
Marriage and Civil Unions	$105,000	<1%	$4,100	<1%
Military Inclusion	$870,000	<1%	$821,053	1%
Nondiscrimination Protections	$5,577,256	4%	$7,422,833	5%
Religious Exemptions	$1,480,500	<1%	$460,200	<1%
Sexual and Reproductive Rights/Justice	$2,898,155	2%	$992,012	1%
Health and Wellbeing	$27,645,366	20%	$25,612,314	16%
Cancer	$64,750	<1%	$602,497	<1%
Cultural Competence and Data Collection	$595,224	<1%	$1,245,916	1%
General Health Services and Health Promotion	$6,314,473	5%	$5,908,916	4%
HIV/AIDS	$17,634,537	13%	$15,912,711	10%
Insurance Coverage	$62,665	<1%	$95,000	<1%
Mental Health, Substance Abuse, and Suicide Prevention	$1,919,956	1%	$1,512,605	1%
Primary Care	$129,012	<1%	$130,478	<1%
Sexual and Reproductive Health	$924,750	1%	$204,191	<1%
Strengthening Communities, Families, and Visibility	$27,106,304	20%	$24,996,864	16%
Community Building and Empowerment	$11,748,930	9%	$12,080,027	8%
Religion	$3,483,607	3%	$1,882,940	1%
Strengthening Families	$1,028,295	1%	$2,502,577	2%
Visibility	$10,845,472	8%	$8,481,320	5%
Education and Safe Schools	$8,785,516	6%	$6,105,406	6%
Education	$4,301,487	3%	$2,879,025	2%
Safe Schools	$4,484,029	3%	$3,226,381	4%

Detailed Breakdown of Issues Addressed in Domestic Funding (cont.)

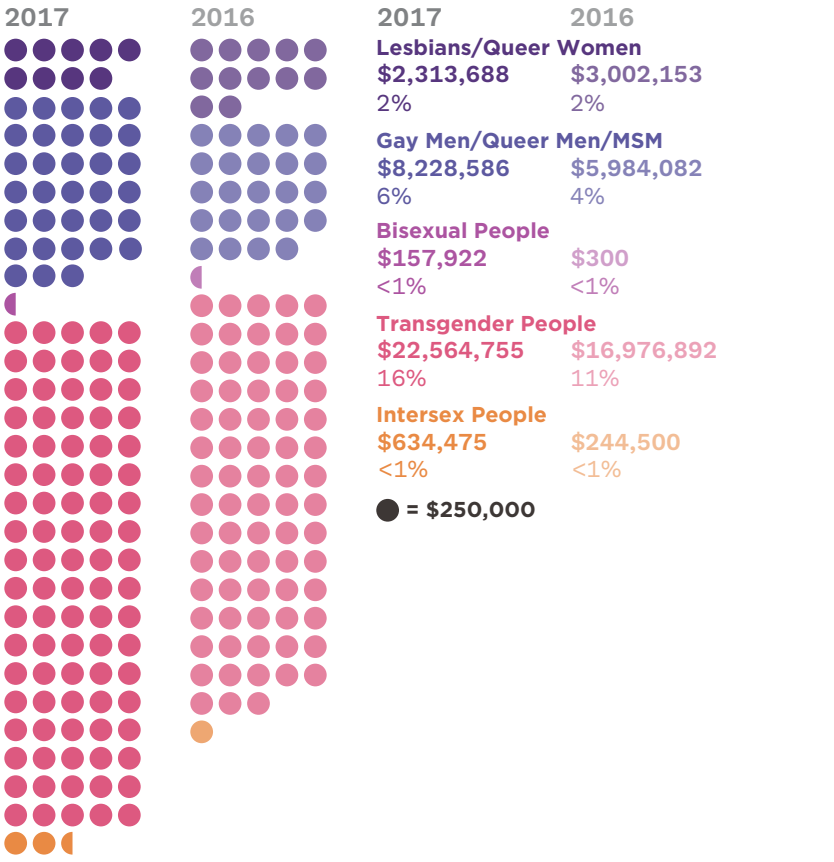
Economic Issues	$6,616,290	5%	$6,028,559	4%
Food Security	$289,075	<1%	$531,800	<1%
Housing and Homelessness	$5,164,531	4%	$4,105,736	3%
Labor and Employment	$1,162,684	1%	$1,391,023	1%
Addressing Violence, Homophobia, Biphobia, and Transphobia	$6,258,023	5%	$31,564,421	20%
Anti-Violence	$4,534,791	3%	$30,610,939	19%
Gun Control	$0	0%	$26,500	<1%
Homophobia, Biphobia, and Transphobia	$1,723,232	1%	$926,982	1%
Other Issues	$8,088,611	6%	$7,237,623	5%
Multi-Issue	$4,411,454	3%	$2,938,478	3%
Philanthropy	$3,666,520	3%	$4,299,145	2%
Unspecified	$10,636	<1%	$0	<1%
Total	**$137,194,461**		**$156,799,690**	

DOMESTIC POPULATION FOCUS

As in previous years, the vast majority of domestic grant dollars were awarded to organizations and programs that serve LGBTQ people generally. Only 24 percent of grant dollars singled out a specific segment of the LGBTQ population.

Funding for trans communities in the United States reached another record high in 2017. At $22.6 million, funding for U.S. trans communities increased by 33 percent.

Distribution of Domestic Grant Dollars by Sexual Orientation, Gender Identity, and Sex Characteristics



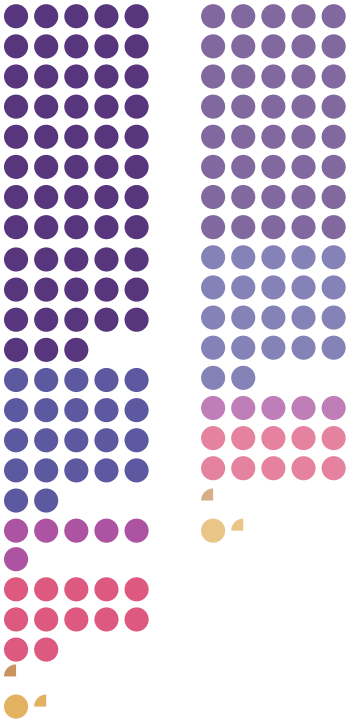
In 2017, funding for LGBTQ communities of color totaled $26.6 million. If you exclude OneOrlando Fund grantmaking from the last two years, this year would represent a new record high in funding for LGBTQ communities of color - going from $20 million without OneOrlando Fund grantmaking in 2016 to $24.5 million without OneOrlando Fund grantmaking in 2016.

This increase was driven by a nearly $4 million increase in funding for communities of color in general and a more $500,000 increase in funding for LGBTQ Latinx communities.

Excluding OneOrlando Fund, the top ten funders of LGBTQ communities of color in 2017 were: Borealis Philanthropy, Gilead Sciences, Arcus Foundation, Ford Foundation, Astraea Lesbian Foundation for Justice, The California Endowment, ViiV Healthcare, Elton John AIDS Foundation, Groundswell Fund, and Tides Foundation. Together they awarded $13.8 million, or 52 percent of all funding for LGBTQ communities of color.

HIV/AIDS was the most funded issue, with 16 percent of all funding for LGBTQ communities of color focused on HIV/AIDS.

Distribution of Domestic Grant Dollars Among People of Color



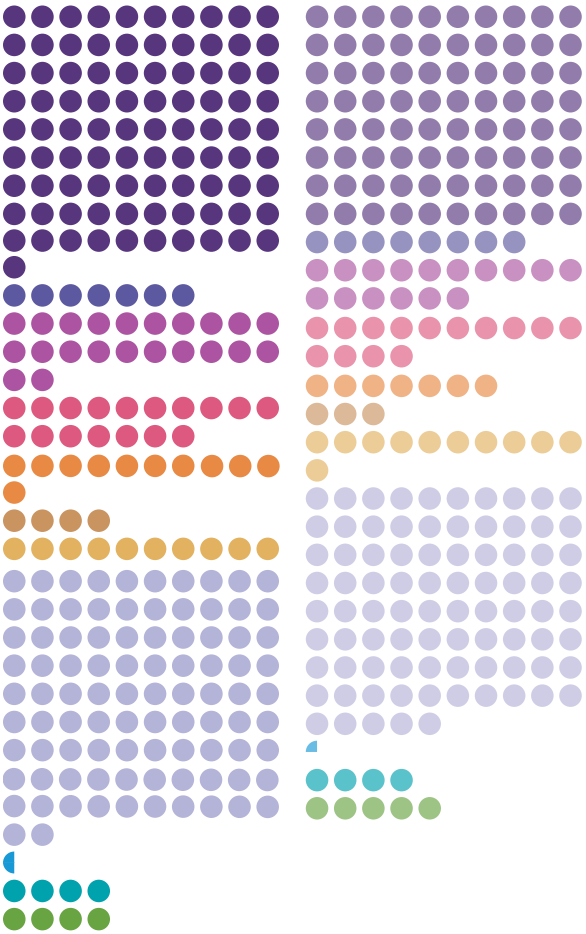
	2017	2016
People of Color (General)	$14,424,956	$10,656,780
	11%	7%
African American/Black	$5,404,187	$5,376,926
	4%	3%
Asian American/Pacific Islander	$1,389,895	$1,153,582
	1%	1%
Latinx	$2,961,139	$2,463,603
	2%	2%
	$5,067,665 (including OneOrlando Fund)	$31,973,693 (including OneOrlando Fund)
Middle Eastern	$7,000	$11,000
	<1%	<1%
Native American	$272,500	$311,750
	<1%	<1%

● = $250,000

Funding for LGBTQ children and youth, which is historically the most funded subpopulation, reached a new record high in 2017 of $25.2 million after a $5.1 million or 26 percent increase.

Funding for LGBTQ people who are homeless or marginally housed, immigrants or refugees, currently or formerly incarcerated, or living with HIV/AIDS also increased by more than $500,000 across each sub-population.

Distribution of Domestic Grant Dollars Among Other Populations

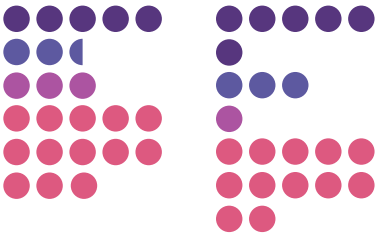


	2017	2016
Children and Youth	$25,517,935	$20,108,727
	19%	13%
Economically Disadvantaged People	$1,705,081	$1,914,296
	1%	1%
Homeless and Marginally Housed People	$5,445,734	$4,032,873
	4%	3%
Immigrants and Refugees	$4,208,250	$3,505,247
	3%	2%
Incarcerated/Formerly Incarcerated People	$2,791,300	$1,857,686
	2%	1%
Military Service Members and Veterans	$1,012,750	$848,553
	1%	1%
Older Adults	$2,413,704	$2,839,532
	2%	2%
People Living with HIV/AIDS (PLWHA)	$23,204,417	$21,357,679
	17%	14%
People with Disabilities	$125,370	$85,000
	1%	<1%
Sex Workers	$990,950	$953,580
	1%	1%
Survivors of Violence	$897,793	$1,362,951
	1%	1%
Survivors of Violence (Including OneOrlando Fund)	$3,004,319	$30,872,951

● = $250,000

In 2017, funding for people of faith increased 10 percent to $5.9 million, up from $5.4 million in 2016. Noticeably, funding for LGBTQ Muslims more than tripled, but still is less than $1 million a year. The Arcus Foundation and the Evelyn and Walter Haas, Jr. Fund were the top two funders of LGBTQ people of faith, collectively providing 56 percent of the funding.

Distribution of Domestic Grant Dollars Among People of Faith



	2017	2016
Christians	$1,302,443 1%	$1,447,972 1%
Jewish People	$647,064 <1%	$746,579 <1%
Muslims	$723,500 <1%	$191,500 <1%
People of Faith (General)	$3,240,937 2%	$2,981,256 2%

● = $250,000

DOMESTIC FUNDING BY TYPE OF ORGANIZATION

LGBTQ ORGANIZATIONS VS. NON-LGBTQ ORGANIZATIONS

Of the $137 million in domestic funding for LGBTQ communities, $132 million was awarded to organizations and $5 million supported individuals. LGBTQ organizations, those whose missions explicitly focus on LGBTQ issues, were awarded $85.2 million or 64 percent of funding for domestic organizations. Non-LGBTQ organizations that received funding for an LGBTQ-specific campaign, program, project, or outreach effort were awarded $46.3 million or 35 percent of funding for domestic organizations.

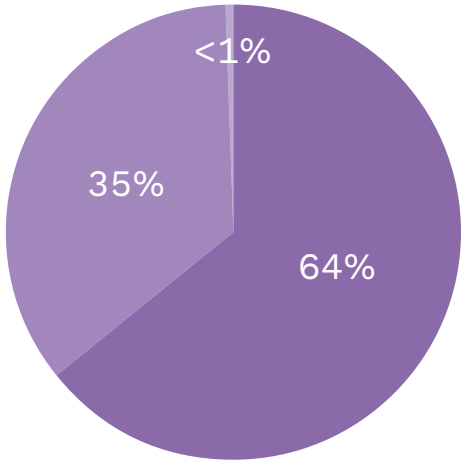
Examples of non-LGBTQ organizations receiving significant funding for LGBTQ work in 2017 include HIV/AIDS service providers such as the Southern AIDS Coalition and Desert AIDS Project, as well as non-profits such as Media Matters for America and Forward Together.

Funding for LGBTQ organizations increased by approximately $3.3 million, while funding for non-LGBTQ organizations increased by $3.5 million. Funding for unnamed or anonymous organizations increased in 2017 but continued to account for less than one percent of funding to domestic organizations.

For the second year in a row, the percentage of funding for domestic LGBTQ organizations decreased relative to funding to non-LGBTQ organizations, accounting for less than two-thirds of domestic funding for the first time since we began tracking funding by organization type.

NOTE: All figures in this section exclude the $5 million awarded to individuals. That funding includes ongoing direct victim support for individuals affected by the Pulse Nightclub Massacre as well as scholarships and fellowships.

Breakdown of Domestic Grant Dollars by Recipient Type: LGBTQ vs. Non-LGBTQ



LGBTQ Organizations
$85,241,996

Non-LGBTQ Organizations
$46,370,521

Unspecified
$609,659

BREAKDOWN OF DOMESTIC FUNDING FOR LGBTQ ORGANIZATIONS

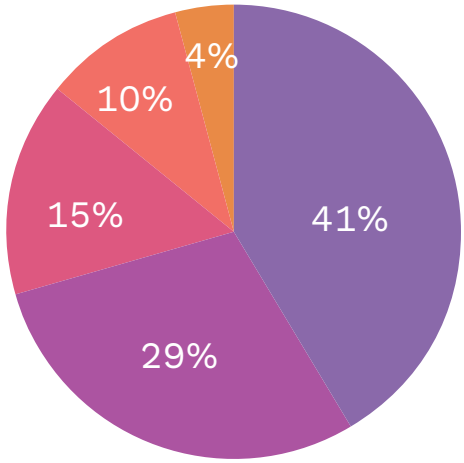
While advocacy organizations continue to capture the largest share of funding for LGBTQ organizations in the United State, the percentage of funding for LGBTQ **advocacy organizations** decreased slightly to 41 percent, down from 45 percent reported in 2016. LGBTQ advocacy organizations with a national scope receive over 20 percent of this funding, followed by organizations focusing on litigation and legal services and state-based advocacy organizations, receiving 10 and 9 percent of funding respectively. Funding for local advocacy organizations increased in 2017, from $1.7 million in 2016 to nearly $3 million, or 3 percent of funding for advocacy organizations.

Service providers received the second highest share of funding for domestic LGBTQ organizations, accounting for just over $25.2 million or nearly 30 percent of funding in 2017, a total consistent with 2016 funding levels. Of this funding, twelve percent was directed towards community centers, which received the largest share of funding to service providers. Funding for community centers increased to $10.5 million, up from $8.4 million in 2016.

Funding for **infrastructure organizations** increased from $9 million in 2016 to nearly $13 million in 2017, to account for 15 percent of all funding for domestic LGBTQ organizations. This growth was driven largely by increases in funding to LGBTQ public foundations as well as funding for research institutes such as the Williams Institute.

Funding remained consistent for the remaining categories of LGBTQ domestic organizations, with only minor fluctuations. **Grassroots community groups**—including faith-based groups, GSA networks, and pride organizations—captured 10 percent of funding for domestic LGBTQ organizations, followed by **arts and culture organizations**, which received 4 percent of funding.

Domestic Grant Dollars for LGBTQ Organizations, by Recipient Organization Type



- **Advocacy Organizations** 41%
- **Service Providers** 29%
- **Infrastructure Organizations** 15%
- **Grassroots Community Groups** 10%
- **Arts and Culture Organizations** 4%

Breakdown of Domestic Grant Dollars for LGBTQ Organizations, By Recipient Organization Type and Sub-Type

Organization Type / Sub-Type	2017	%	2016	%
Advocacy Organizations	**$35,112,584**	**41%**	**$36,843,312**	**45%**
National Advocacy Organizations	$14,468,217	17%	$16,303,941	20%
Regional Advocacy Organizations	$1,653,414	2%	$1,395,147	2%
State Advocacy Organizations	$7,668,465	9%	$7,286,035	9%
Local Advocacy Organizations	$2,813,725	3%	$1,750,085	2%
Litigation & Legal Services Organizations	$8,508,764	10%	$10,108,103	12%
Arts and Culture Organizations	**$3,614,910**	**4%**	**$3,362,793**	**4%**
Grassroots Community Groups	**$8,352,224**	**10%**	**$6,786,702**	**8%**
Athletic Groups	$158,810	<1%	$315,630	<1%
Business/Professional Networks	$1,149,137	1%	$431,450	1%
Faith-based Groups	$1,228,046	1%	$1,617,548	2%
Family Groups	$204,615	<1%	$850,082	1%
GSA Networks or Campus Groups	$2,849,505	3%	$1,974,420	2%
Pride Organizations	$487,615	1%	$241,230	<1%
Social and Recreational Groups	$0	<1%	$6,000	<1%
Infrastructure Organizations	**$12,841,285**	**15%**	**$9,094,742**	**11%**
Philanthropic Networks	$1,865,650	2%	$1,011,677	1%
Public Foundations	$4,891,525	6%	$3,404,168	4%
Research Institutes	$3,970,970	5%	$2,813,153	3%
Technical Assistance Provider and Networks	$2,113,140	2%	$1,865,744	2%
Service Providers	**$25,016,312**	**29%**	**$25,634,977**	**31%**
Aging Service Providers	$1,304,069	2%	$2,091,843	3%
Community Centers	$10,186,827	12%	$8,404,747	10%
Health Centers	$2,808,980	3%	$3,041,375	4%
HIV/AIDS Service Providers	$3,367,640	4%	$5,272,270	6%
Other Service Providers	$2,896,454	3%	$2,329,546	3%
Support Groups	$81,050	<1%	$72,275	<1%
Youth Service Providers	$4,371,292	5%	$4,422,922	5%
Universities and Post-Secondary Schools	**$29,680**	**<1%**	**$89,971**	**<1%**
Campus Groups	$500	<1%	$23,160	<1%
High Schools	$25,180	<1%	$66,811	<1%
Unspecified	**$0**	**<1%**	**$188,313**	**<1%**
Grand Total	**$85,241,996**		**$81,813,997**	

BREAKDOWN OF DOMESTIC FUNDING FOR NON-LGBTQ ORGANIZATIONS

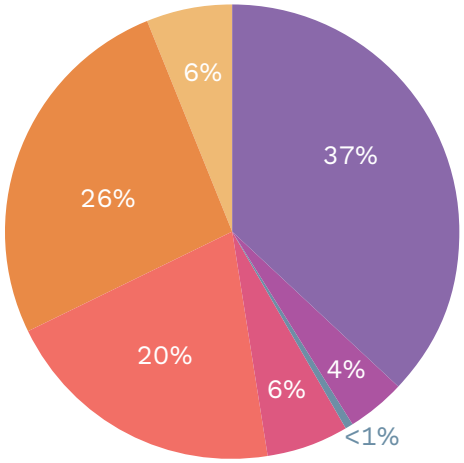
Advocacy organizations continued to capture the largest share of funding for non-LGBTQ organizations, accounting for almost $17 million or 37 percent of all funding for non-LGBTQ organizations in 2017. This represents an increase of over $4 million from 2016.

Funding for non-LGBTQ **service providers** takes the second largest share of funding, accounting for 26 percent or $12.1 million dollars in 2017, representing a slight increase from the $10.6 million reported in 2016. This category is carried by the $5.4 million for non-LGBTQ HIV/AIDS service providers funded for targeted work with LGBTQ populations.

Infrastructure organizations continue to receive a significant portion of funds for non-LGBTQ organizations in the United States. These organizations — including public foundations, research institutes, and philanthropic networks — collectively received $9.2 million, or 20 percent of funding for non-LGBTQ organizations in 2017.

While funding for non-LGBTQ organizations increased overall, some categories of organizations did see a decrease in funding in 2017. Support for non-LGBTQ **arts and culture organizations**, **grassroots community groups**, and **universities and schools** all saw modest decreases.

Domestic Grant Dollars for Non-LGBTQ Organizations, by Recipient Organization Type



- **Advocacy Organizations** 37%
- **Arts and Culture Organizations** 4%
- **Government/Intergovernmental Agencies** <1%
- **Grassroots Community Groups** 6%
- **Infrastructure Organizations** 20%
- **Service Providers** 26%
- **Universities and Schools** 6%

Breakdown of Domestic Grant Dollars for Non-LGBTQ Organizations, By Recipient Organization Type and Sub-Type

Organization Type / Sub-Type	2017	%	2016	%
Advocacy Organizations	**$16,955,696**	**37%**	**$12,892,866**	**30%**
National Advocacy Organizations	8,469,464	18%	$7,101,007	17%
Regional Advocacy Organizations	$2,194,219	5%	$520,081	1%
State Advocacy Organizations	$1,608,951	3%	$1,222,939	3%
Local Advocacy Organizations	$2,770,647	6%	$1,684,532	4%
Litigation & Legal Services Organizations	$1,912,415	4%	$2,358,307	6%
Arts and Culture Organizations	**$2,044,167**	**4%**	**$3,698,477**	**9%**
Government Agencies (Including Public School Systems)	**$5,000**	**<1%**	**$62,850**	**<1%**
Grassroots Community Groups	**$2,946,312**	**6%**	**$3,002,681**	**7%**
Athletic Groups	$0	<1%	$1,000	<1%
Business/Professional Networks	$555,800	1%	$916,700	2%
Faith-based Groups	$1,213,237	3%	$738,695	2%
Social and Recreational Groups	$5,000	<1%	$1,000	<1%
Infrastructure Organizations	**$9,296,762**	**20%**	**$9,404,028**	**22%**
Philanthropic Networks	$825,367	2%	$966,991	2%
Public Foundations	$4,799,995	10%	$3,869,872	9%
Research Institutes	$1,679,200	4%	$3,290,200	8%
Technical Assistance Provider and Networks	$1,992,200	4%	$1,276,965	3%
Service Providers	**$12,199,142**	**26%**	**$10,664,612**	**25%**
Aging Service Providers	$67,5850	<1%	$20,100	<1%
Community Centers	$349,274	1%	$144,537	<1%
Health Centers	$2,175,436	5%	$1,815,087	4%
HIV/AIDS Service Providers	$5,534,735	12%	$5,166,619	12%
Other Service Providers	$1,973,446	4%	$2,221,276	5%
Support Groups	$35,000	0%	$35,000	<1%
Youth Service Providers	$2,054,667	4%	$1,277,593	3%
Universities and Post-Secondary Schools	**$2,899,992**	**6%**	**$3,148,968**	**7%**
Campus Groups	$62,552	<1%	$6,250	<1%
High Schools	$9,650	<1%	$6,250	<1%
Universities	$2,827,790	6%	$3,148,968	7%
Grand Total	**$46,370,521**		**$42,874,483**	

GLOBAL FUNDING FOR LGBTQ ISSUES

In 2017, U.S.-based foundations awarded 754 grants totaling $48.5 million to support international LGBTQ issues and LGBTQ communities outside the U.S. This figure does not include an additional 17 grants totaling $3.6 million awarded to intermediaries for international re-granting. This represents an increase of 6 percent from the $45.5 million awarded in 2016, setting a new record for grantmaking for LGBTQ issues outside the United States by U.S.-based foundations for the second year in a row.

Grantmaking outside of the United States accounted for approximately 26 percent of grantmaking by U.S. foundations.

NOTE: This section explores funding from foundations, corporations, and nonprofit grantmakers based in the United States. It does not include LGBTQ funding from foundations and funding institutions outside the U.S. or governments and multilateral organizations. The *2015-2016 Global Resources Report,* published in April of 2018 by Funders for LGBTQ Issues in partnership with the Global Philanthropy Project, tracks philanthropic support for LGBTQ issues globally and includes those grantmakers.

NOTE: The list of top grant recipients excludes dollars awarded for re-granting purposes. Multi-year grants are counted for the full amount in the year they are awarded.

TOP 10 U.S.-BASED GLOBAL LGBTQ FUNDERS[9]

1. **Ford Foundation**
   $7,415,000
   New York, NY
2. **Arcus Foundation**
   $7,277,755
   New York, NY
3. **Open Society Foundations**
   $6,961,001
   New York, NY
4. **Tides Foundation**
   $4,088,640
   San Francisco, CA
5. **Foundation for a Just Society**
   $3,800,000
   New York, NY
6. **M.A.C. AIDS Fund**
   $2,846,389
   New York, NY
7. **Astraea Lesbian Foundation for Justice**
   $2,324,879
   New York, NY
8. **American Jewish World Service**
   $1,924,369
   New York, NY
9. **Gilead Sciences**
   $1,632,847
   Foster City, CA
10. **Andrew W. Mellon Foundation**
    $1,159,000
    New York, NY

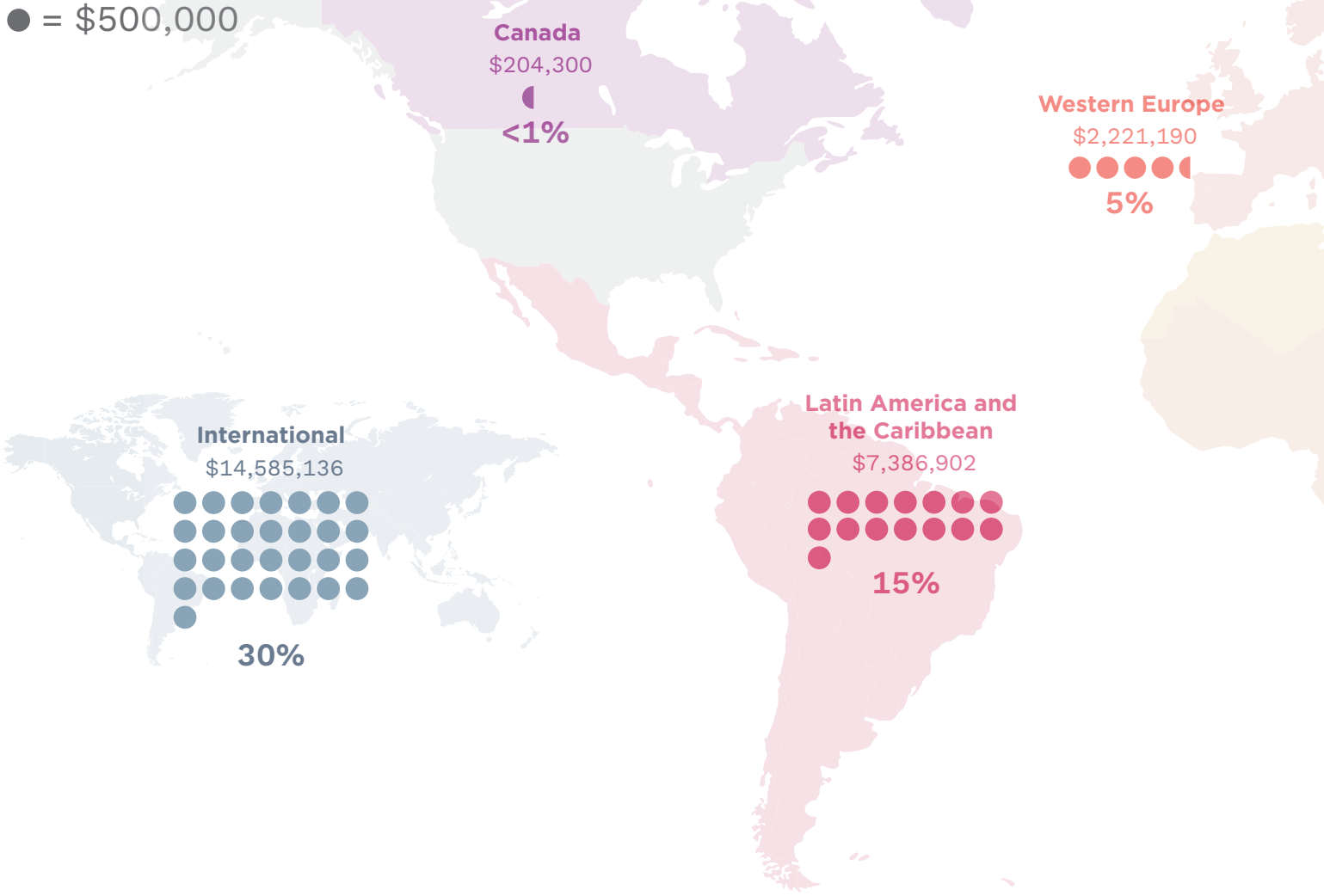
TOP 10 GLOBAL LGBTQ GRANTEES OF U.S.-BASED FUNDERS[10]

1. **African Men for Sexual Health and Rights (AMSHER)**
   $3,000,000
   Johannesburg, South Africa
2. **All Out**
   $2,630,000
   New York, NY
3. **Astraea Lesbian Foundation for Justice**
   $1,580,005
   New York, NY
4. **Initiative Sankofa d'Afrique de l'Ouest (ISDAO)**
   $1,500,000
   Nairobi, Kenya
5. **University of the Western Cape**
   $1,159,000
   Cape Town, South Africa
6. **Collective Foundation AIDS Accountability International**
   $1,150,000
   Södermalm, Sweden
7. **Tharthi Myay Foundation**
   $750,000
   Yangon, Myanmar
8. **Partners Asia**
   $750,000
   Oakland, CA
9. **Transgender Europe (TGEU)**
   $700,000
   Berlin, Germany
10. **The Council for Global Equality**
    $665,000
    Washington, DC

[9] In 2017, one anonymous funders awarded a total of $6,360,000 to support LGBTQ issues outside of the United States. If the multiple anonymous funders appeared in the top ten list, they would rank as the fourth largest funder.

[10] In 2016, multiple anonymous grantees received $1,416,919.00 for work benefiting LGBTQ communities outside the United States. If these multiple anonymous grantees appeared in the top ten list, they would rank as the fifth largest grantee.

GLOBAL LGBTQ FUNDING BY REGION AND ISSUES ADDRESSED



International

TOP FUNDER
Arcus Foundation $4,161,755

TOP STRATEGY
Advocacy (57%)

TOP ISSUE ADDRESSED
Civil and Human Rights (79%)

Canada

TOP FUNDER
Elton John AIDS Foundation $337,000

TOP STRATEGY
Direct Service (49%)

TOP ISSUE ADDRESSED
Civil and Human Rights (98%)

Latin America and the Caribbean[11]

TOP FUNDER
M.A.C. AIDS Fund $927,889

TOP STRATEGY
Advocacy (33%)

TOP ISSUE ADDRESSED
Civil and Human Rights (57%)

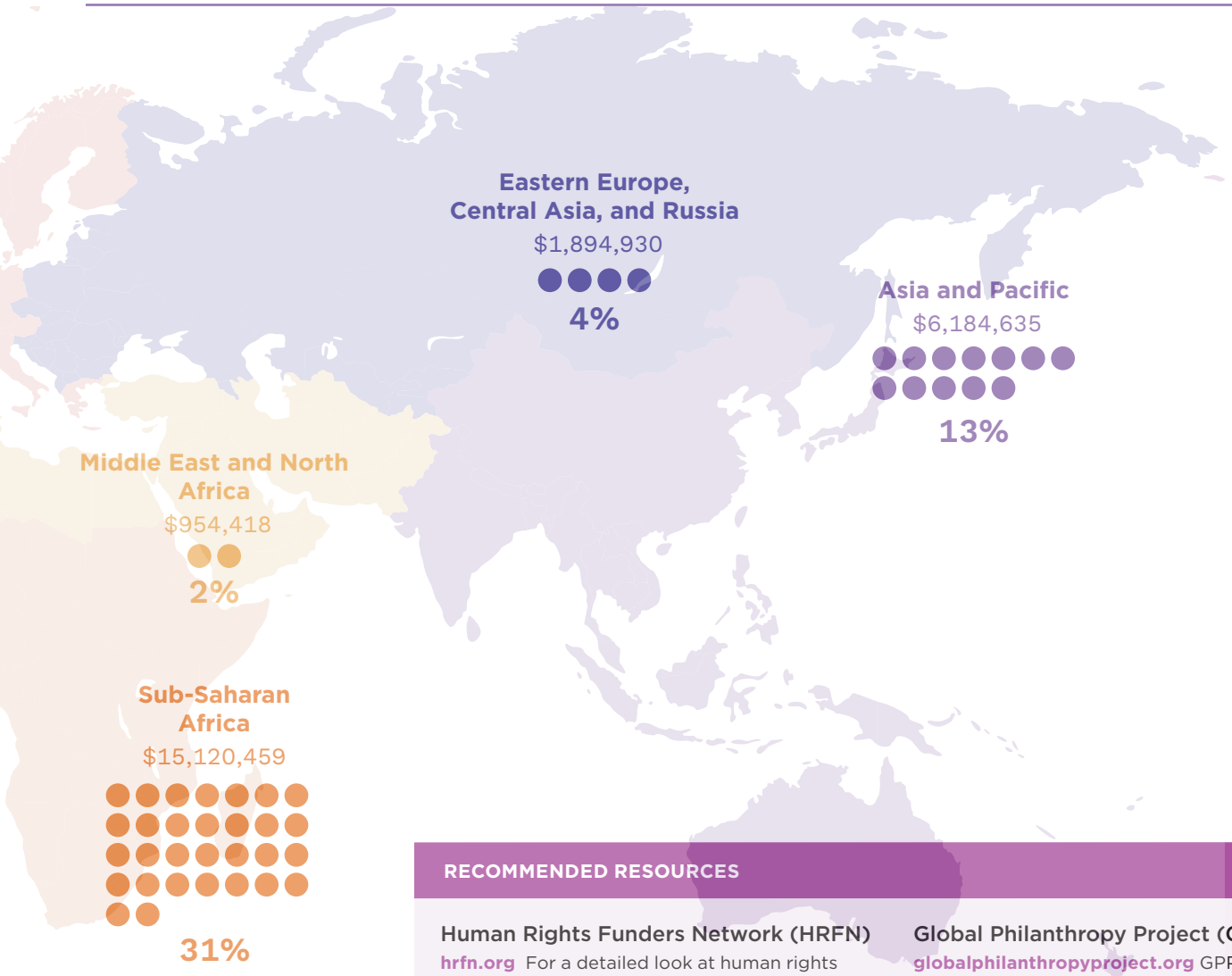
Western Europe

TOP FUNDER
M.A.C. AIDS Fund $830,000

TOP STRATEGY
Advocacy (28%)

TOP ISSUE ADDRESSED
Health and Wellbeing (75%)

[11] In 2017, multiple anonymous funders awarded a total of $2,080,000 to support LGBTQ issues in Latin America and The Caribbean. If the multiple anonymous funders appeared as one funder, they would rank [illegible] among top funders.



RECOMMENDED RESOURCES

Human Rights Funders Network (HRFN)

hrfn.org For a detailed look at human rights funding around the world, see "Advancing Human Rights: The State of Global Foundation Grantmaking," produced by HRFN and the Foundation Center. The most recent report found that foundations awarded $2.4 billion for human rights in 2015, of which about 4 percent ($101.8 million) focused on LGBT populations. Interactive data is available at **humanrightsfunding.org.**

Global Philanthropy Project (GPP)

globalphilanthropyproject.org GPP is a global network of funders and philanthropic advisors working to expand global philanthropic support to advance the human rights of lesbian, gay, bisexual, transgender and intersex (LGBTI) people in the Global South and East. GPP's website, **globalphilanthropyproject.org**, provides an array of resources on grantmaking for LGBTI issues around the world.

Sub-Saharan Africa[12]

TOP FUNDER
Ford Foundation
$6,200,00

TOP STRATEGY
Advocacy (62%)

TOP ISSUE ADDRESSED
Civil and Human Rights (68%)

Middle East and North Africa

TOP FUNDER
Arcus Foundation
$300,000

TOP STRATEGY
Philanthropy and Fundraising (31%)

TOP ISSUE ADDRESSED
Civil and Human Rights (49%)

Eastern Europe, Central Asia, and Russia

TOP FUNDER
Open Society Foundations
$736,000

TOP STRATEGY
Advocacy (78%)

TOP ISSUE ADDRESSED
Civil and Human Rights (80%)

Asia and Pacific

TOP FUNDER
Foundation for a Just Society $1,950,000

TOP STRATEGY
Advocacy (42%)

TOP ISSUE ADDRESSED
Civil and Human Rights (74%)

[12] In 2016, multiple anonymous funders awarded a total of $3,230,000 to support LGBTQ issues in Sub-Saharan Africa. If the multiple anonymous funders appeared as one funder, they would rank as the number 4 funder.

GLOBAL FUNDING BY LOCATION OF GRANTEE

In 2017, 25 percent of all funding for global LGBTQ issues was awarded to a grantee physically located in the United States. Another 12 percent of funding for global LGBTQ work was awarded to grantees physically located in Western Europe. Over 60 percent of global funding by U.S. foundations reached organizations that were physically located outside of Western Europe and the United States.

This chart shows the country locations of grantees that received U.S. foundation funding for LGBTQ issues in 2017. For each geographic area, the chart shows the amount of funding for each country in the region. It also shows the funding for work focused on the region, but conducted by organizations based outside the region. Some funding was devoted to organizations in undisclosed locations, and that total amount is listed for each region.

Global Funding by Location of Grantee

Asia and Pacific	$6,184,635
Regional Funding for Organizations Based Within Asia and Pacific	
Australia	$288,975
Bangladesh	$30,000
Cambodia	$40,000
China	$20,000
Fiji	$21,000
Hong Kong	$20,000
India	$1,059,381
Indonesia	$106,000
Japan	$117,700
Mongolia	$80,000
Myanmar	$1,215,000
Nepal	$74,560
New Zealand	$30,000
Pakistan	$65,480
Philippines	$258,134
Samoa	$22,500
Singapore	$162,000
South Korea	$24,545
Sri Lanka	$25,000
Taiwan	$179,000
Thailand	$696,540
Timor Leste	$1,000
Regional Funding for Organizations Based Outside Asia and Pacific	
Switzerland	$195,620
United Kingdom	$25,000
USA	$1,057,800
Regional Funding for Organizations Based in Undisclosed Countries	
Unspecified	$369,400

Eastern Europe, Central Asia and Russia	$1,894,930
Regional Funding for Organizations Based Within Eastern Europe, Central Asia and Russia	
Armenia	$10,000
Bosnia and Herzegovina	$101,800
Bulgaria	$40,000
Croatia	$102,000
Czech Republic	$100,986
Georgia	$98,700
Hungary	$38,000
Kazakhstan	$28,000
Kyrgyzstan	$216,800
Latvia	$30,000
Lithuania	$90,000
Moldova	$80,000
Montenegro	$40,000
Poland	$101,200
Romania	$50,000
Russia	$236,744
Serbia	$257,000
Slovenia	$32,000
Turkey	$10,000
Ukraine	$132,000
Uzbekistan	$4,700
Regional Funding for Organizations Based Outside Eastern Europe, Central Asia and Russia	
Austria	$20,000
Belgium	$55,000
Regional Funding for Organizations Based in Undisclosed Countries	
Unspecified	$20,000

Latin America and the Caribbean	$7,386,902
Regional Funding for Organizations Based Within Latin America and the Caribbean	
Argentina	$360,000
Belize	$26,800
Brazil	$1,623,000
Chile	$554,500
Colombia	$540,666
Costa Rica	$12,000
Dominican Republic	$226,700
Ecuador	$80,000
El Salvador	$136,600
Grenada	$75,000
Guatemala	$33,000
Guyana	$15,000
Haiti	$88,000
Honduras	$104,500
Jamaica	$792,389
Mexico	$1,524,500
Nicaragua	$286,770
Paraguay	$28,000
Peru	$254,477
St. Lucia	$190,000
Trinidad and Tobago	$10,000
Uruguay	$40,000
Regional Funding for Organizations Based Outside Latin America and the Caribbean	
Switzerland	$50,000
USA	$330,000
Regional Funding for Organizations Based in Undisclosed Countries	
Unspecified	$5,000

Global Funding by Location of Grantee (cont.)

Sub-Saharan Africa	$15,120,459
Regional Funding for Organizations Based Within Sub-Saharan Africa	
Botswana	$127,000
Burkina Faso	$197,000
Burundi	$23,000
Cameroon	$10,000
Democratic Republic of the Congo (DRC)	$32,182
Ghana	$65,000
Ivory Coast	$15,000
Kenya	$4,441,997
Liberia	$102,200
Malawi	$190,000
Namibia	$185,000
Nigeria	$456,500
Rwanda	$65,000
Sénégal	$13,000
South Africa	$5,720,862
Swaziland	$50,000
Sweden	$1,150,000
Tanzania	$80,000
Togo	$200,000
Uganda	$788,219
Zambia	$162,000
Zimbabwe	$69,500
Regional Funding for Organizations Based Outside Sub-Saharan Africa	
United Kingdom	$100,000
USA	$846,999
Regional Funding for Organizations Based in Undisclosed Countries	
Unspecified	$30,000

Middle East and North Africa	$954,418
Regional Funding for Organizations Based Within Middle East and North Africa	
Algeria	$13,700
Egypt	$115,000
Israel	$183,000
Jordan	$5,000
Lebanon	$167,000
Morocco	$67,267
Tunisia	$30,000
Turkey	$73,451
Regional Funding for Organizations Based Outside Middle East and North Africa	
The Netherlands	$300,000

United States and Canada	$137,420,261
Regional Funding for Organizations Based Within the United States and Canada	
Canada	$204,300
United States of America	$137,215,961
Regional Funding for Organizations Based in Undisclosed Countries	
Unspecified	$3,873,444

Western Europe	$2,221,190
Regional Funding for Organizations Based Within Western Europe	
Austria	$7,000
Belgium	$11,935
Denmark	$6,000
France	$138,900
Germany	$582,000
Iceland	$10,000
Ireland	$48,890
Italy	$165,000
Norway	$3,632
Spain	$256,122
The Netherlands	$210,000
United Kingdom	$781,711

International	$14,585,136
International Funding for Organizations Based Around The World	
Australia	$6,000
Austria	$92,000
Belgium	$561,935
Canada	$100,000
Denmark	$6,000
Fiji	$5,200
France	$188,900
Germany	$1,282,000
Iceland	$10,000
Ireland	$48,890
Italy	$165,000
Mexico	$5,000
Namibia	$125,000
Norway	$3,632
Pakistan	$1,451
Russia	$1,638
South Africa	$1,682,000
Spain	$256,122
Sweden	$15,000
Switzerland	$534,163
The Netherlands	$430,000
United Kingdom	$207,854
United Kingdom - England	$942,648
USA	$9,808,893
International Funding for Organizations Based in Undisclosed Countries	
Unspecified	$327,000

COMMUNITY FOUNDATION GRANTMAKING FOR LGBTQ ISSUES

In 2017, community foundations awarded $12.4 million to LGBTQ issues (or $11.7 million after dollars awarded for re-granting are excluded). This is a increase from 2016, when community foundations awarded $6.9, driven in part by increased donor advised grantmaking at community foundations as well as new foundations entering the field. Donor advised funds accounted for 27.5 percent of community foundation grantmaking for LGBTQ issues in 2017.

NOTE: This section includes funding awarded by community foundations from their discretionary funds as well as from their donor-advised funds, which are often driven by recommendations from the donor who originally established the fund.

TOP 10 COMMUNITY FOUNDATIONS

1. **California Community Foundation**
   $2,778,807
   Los Angeles, CA
2. **Greater Kansas City Community Foundation**
   $1,404,750
   Kansas City, Missouri
3. **Silicon Valley Community Foundation**
   $936,112
   Mountain View, CA
4. **The New York Community Trust**
   $815,250
   New York, NY
5. **Arizona Community Foundation**
   $658,276
   Phoenix, AZ
6. **Boston Foundation**
   $625,800
   Boston, MA
7. **Community Foundation for Northeast Florida**
   $545,900
   Jacksonville, FL
8. **Community Foundation of Broward**
   $485,820
   Fort Lauderdale, FL
9. **The Cleveland Foundation**
   $480,250
   Cleveland, OH
10. **Miami Foundation**
    $360,675
    Miami, FL

TOP 10 COMMUNITY FOUNDATION GRANTEES

1. **Human Rights Campaign (HRC) Foundation**
   $2,146,623
   Washington, DC
2. **Desert AIDS Project**
   $1,001,500
   Palm Springs, CA
3. **ONE Community Media, LLC**
   $423,249
   Phoenix, AR
4. **San Francisco AIDS Foundation**
   $378,814
   San Francisco, CA
5. **Lambda Legal Defense and Education Fund**
   $339,708
   New York, NY
6. **Los Angeles LGBT Center**
   $309,457
   Los Angeles, CA
7. **Equality Ohio Education Fund**
   $286,000
   Columbus, OH
8. **The Trevor Project**
   $268,747
   West Hollywood, CA
9. **The Boston Foundation**
   $255,000
   Boston, MA
10. **Jacksonville Area Sexual Minority Youth Network (JASMYN)**
    $245,250
    Jacksonville, FL

CORPORATE GRANTMAKING FOR LGBTQ ISSUES

In 2017, corporate foundation support for LGBTQ issues totaled a record-breaking $27.1 million (or $23.8 million after dollars awarded for re-granting are excluded). This marks a $1.2 million - or 5 percent - increase over last year's record high of $25.9 million. While the 2016 high mark was driven by $9.4 million awarded in response to the Pulse Nightclub Massacre, the 2017 increase is fueled by substantial increases in giving by Gilead Sciences and ViiV Healthcare for HIV/AIDS work in LGBTQ communities.

NOTE: The Committee Encouraging Corporate Philanthropy estimates that corporate foundation giving only accounts for 34 percent of all corporate giving, with direct cash accounting for 48 percent and in-kind giving accounting for 18 percent. Currently, our corporate data only includes corporate foundation grantmaking and employee matching gift programs run through corporate foundations with some direct cash included if the company self reports. It does not include all of the generous support from corporations giving without an official foundation or philanthropic office or in-kind gifts.

TOP 10 CORPORATE FUNDERS

1. **Gilead Sciences**
   $11,730,648
   Foster City, CA
2. **M.A.C. AIDS Fund**
   $4,963,389
   New York, NY
3. **Wells Fargo**
   $3,339,971
   San Francisco, CA
4. **ViiV Healthcare**
   $2,982,325
   Research Triangle, NC
5. **Levi Strauss Foundation**
   $1,045,500
   San Francisco, CA
6. **Google**
   $1,000,000
   Mountain View, CA
7. **Bank of America Charitable Foundation**
   $289,488
   Charlotte, NC
8. **Citi Foundation**
   $250,000
   Long Island City, NY
9. **Polk Bros. Foundation**
   $243,500
   Chicago, IL
10. **Blue Shield of California Foundation**
    $227,000
    San Francisco, CA

TOP 10 CORPORATE GRANTEES

1. **Southern AIDS Coalition**
   $1,751,219
   Atlanta, GA
2. **New York LGBT Center**
   $1,040,583
   New York, NY
3. **Los Angeles LGBT Center**
   $800,124
   Los Angeles, CA
4. **Annenberg Center for Health Sciences at Eisenhower**
   $756,250
   Rancho Mirage, CA
5. **Casa Ruby**
   $600,000
   Washington, DC
6. **Elton John AIDS Foundation**
   $587,500
   New York, NY
7. **San Francisco AIDS Foundation**
   $521,339
   San Francisco, CA
8. **Point Foundation**
   $510,500
   Los Angeles, CA
9. **Elton John AIDS Foundation (UK)**
   $500,000
   London, England
10. **Fund for Public Health in New York, Inc.**
    $500,000
    New York, NY

RECOMMENDED RESOURCE

Committee Encouraging Corporate Philanthropy

A great resource for a more detailed look at corporate philanthropy is ***Giving in Numbers: 2018 Edition*** by the Committee Encouraging Corporate Philanthropy. The report and more can be found at **www.cecp.co**

PRIVATE FOUNDATION GRANTMAKING FOR LGBTQ ISSUES

In 2017, private foundations awarded $93.4 million to LGBTQ issues (or $87.3 million after dollars for re-granting are excluded). This represents a $4.7 million increase from the record high reported in 2016. Non-LGBTQ private foundations increased their grantmaking by $4.3 million while LGBTQ private foundations increased their grantmaking only slightly, by less than one million dollars.

Consistent with historical trends, private foundations continue to represent the largest slice of LGBTQ funding, accounting for nearly half of all foundation funding in 2017.

TOP 10 LGBTQ PRIVATE FOUNDATIONS

1. **Arcus Foundation**
   $17,006,755
   New York, NY
2. **Gill Foundation**
   $9,520,007
   Denver, CO
3. **H. van Ameringen Foundation**
   $4,349,500
   New York, NY
4. **Alphawood Foundation**
   $1,686,500
   Chicago, IL
5. **Tawani Foundation**
   $1,648,000
   Chicago, IL
6. **David Bohnett Foundation**
   $1,393,481
   Los Angeles, CA
7. **Amy Mandel and Katina Rodis Fund**
   $1,185,210
   Asheville, NC
8. **Palette Fund**
   $1,114,325
   New York, NY
9. **Calamus Foundation**
   $647,000
   New York, NY
10. **Bastian Foundation, B. W.**
    $625,070
    Oren, UT

TOP 10 NON-LGBTQ PRIVATE FOUNDATIONS

1. **Ford Foundation**
   $12,445,000
   New York, NY
2. **Open Society Foundations**
   $7,769,598
   New York, NY
3. **Evelyn & Walter Haas, Jr. Fund**
   $5,038,200
   San Francisco, CA
4. **Foundation for a Just Society**
   $4,640,000
   New York, NY
5. **The California Endowment**
   $3,780,111
   Los Angeles, CA
6. **John D. and Catherine T. MacArthur Foundation**
   $1,425,000
   Chicago, IL
7. **Andrew W. Mellon Foundation**
   $1,159,000
   New York, NY
8. **William and Flora Hewlett Foundation**
   $1,125,000
   Menlo Park, CA
9. **Meyer Memorial Trust**
   $955,856
   Portland, OR
10. **Marguerite Casey Foundation**
    $822,500
    Seattle, WA

TOP 10 PRIVATE FOUNDATION GRANTEES[13]

1. **African Men for Sexual Health and Rights (AMSHER**
   $3,000,000
   Johannesburg, South Africa
2. **Genders & Sexualities Alliance Network**
   $2,580,455
   Oakland, CA
3. **National Center for Lesbian Rights (NCLR)**
   $1,545,000
   San Francisco, CA
4. **Astraea Lesbian Foundation for Justice**
   $1,510,200
   New York, NY
5. **Initiative Sankofa d'Afrique de l'Ouest (ISDAO)**
   $1,500,000
   Nairobi, Kenya
6. **Freedom for All Americans**
   $1,205,000
   Washington, DC
7. **Equality California Institute**
   $1,177,500
   Los Angeles, CA
8. **University of the Western Cape**
   $1,159,000
   Cape Town, South Africa
9. **Equality Federation Institute**
   $1,152,500
   San Francisco, CA
10. **Collective Foundation AIDS Accountability International**
    $1,150,000
    Södermalm, Sweden

[13] NOTE: Anonymous grantees received a total of $1,448,960 for all arrival foundations. If they were one grantee, they would appear in the top ten list at number six.

PUBLIC FUNDER GRANTMAKING FOR LGBTQ ISSUES

In 2017, public foundations awarded $50.4 million to LGBTQ issues (or $49.8 million after dollars awarded for regranting are excluded). This represents a significant decrease of $36.8 million from 2016, when nearly $40 million in direct victim support following the Pulse Nightclub massacre elevated public foundation LGBTQ giving to an all time high of nearly $90 million.

The percentage of donor advised grantmaking from public foundations increased from eleven percent in 2016 to 20 percent in 2017.

TOP 10 LGBTQ PUBLIC FUNDERS

1. **Astraea Lesbian Foundation for Justice**
   $5,168,495
   New York, NY
2. **Elton John AIDS Foundation**
   $4,966,500
   New York, NY
3. **Horizons Foundation**
   $1,644,979
   San Francisco, CA
4. **Pride Foundation**
   $1,200,468
   Seattle, WA
5. **Black Tie Dinner**
   $1,154,999
   Dallas, TX
6. **Point Foundation**
   $818,668
   Los Angeles, CA
7. **Our Fund**
   $738,207
   Wilton Manors, FL
8. **Our Fund – Contigo Fund**
   $614,824
   Orlando, FL
9. **Funders for LGBTQ Issues**
   $505,000
   New York, NY
10. **Trans Justice Funding Project**
    $500,500
    New York, NY

TOP 10 NON-LGBTQ PUBLIC FUNDERS

1. **Tides Foundation**
   $7,596,762
   San Francisco, CA
2. **Borealis Philanthropy**
   $3,181,800
   Minneapolis, MN
3. **Strengthen Orlando - OneOrlando Fund**
   $2,106,525
   Orlando, FL
4. **American Jewish World Service**
   $1,984,369
   New York, NY
5. **NEO Philanthropy**
   $1,319,985
   New York, NY
6. **Groundswell Fund**
   $1,171,554
   Oakland, CA
7. **Robin Hood Foundation**
   $1,109,500
   New York, NY
8. **Broadway Cares/Equity Fights AIDS**
   $1,061,263
   New York, NY
9. **New York Women's Foundation**
   $959,500
   New York, NY
10. **amfAR, Foundation for AIDS Research**
    $950,122
    New York, NY

TOP 10 PUBLIC FUNDER GRANTEES[14]

1. **All Out**
   $2,330,000
   New York, NY
2. **New York LGBT Center**
   $1,297,580
   New York, NY
3. **Transgender Law Center**
   $941,098
   Oakland, CA
4. **Human Rights Campaign (HRC) Foundation**
   $595,225
   Washington, DC
5. **GMHC**
   $536,269
   New York, NY
6. **Gay and Lesbian Leadership Institute (Victory Institute)**
   $509,212
   Washington, DC
7. **International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA)**
   $496,163
   Geneva, Switzerland
8. **Hetrick-Martin Institute (HMI)**
   $465,472
   New York, NY
9. **BreakOUT!**
   $457,500
   New Orleans, LA
10. **Southerners On New Ground (SONG)**
    $412,922
    Atlanta, GA

[14] Anonymous grantees received a total of $4,886,665 from public funders - which includes $2.1 million in victim support distributed in a second round of payments following the Pulse Nightclub Massacre in Orlando. If they were organized they would appear in the top ten list in the top spot.

APPENDIX: 2017 LIST OF LGBTQ GRANTMAKERS IN THE U.S.

FOUNDATION NAME	Total Grants	Direct Grant Dollars	Regranting Dollars	Total Dollars
AARP Foundation	1	$15,000		$15,000
AbbVie Foundation	1	$10,000		$10,000
Abelard Foundation	1	$10,500		$10,500
Adams Memorial Fund, Frank W. & Carl S.	2	$15,400		$15,400
Advocates for Youth	3	$52,480		$52,480
Aetna Foundation	1	$ 1,000		$ 1,000
Ahmanson Foundation	1	$ 7,500		$ 7,500
AHS Foundation	4	$81,000		$81,000
AIDS Foundation of Chicago	7	$52,185		$52,185
AIDS Funding Collaborative	6	$136,021		$136,021
AIDS United	17	$567,500		$567,500
Akron Community Foundation	2	$ 6,000		$ 6,000
Allstate Foundation	1	$ 1,000		$ 1,000
Ally Financial	1	$ 1,575		$ 1,575
Alphawood Foundation	29	$1,686,500		$ 1,686,500
Altman Foundation, Jeffrey A.	1	$ 5,000		$ 5,000
Amalgamated Bank	1	$ 2,500		$ 2,500
American Express Foundation	1	$100,000		$100,000
American Institute of Bisexuality	8	$200,776		$200,776
American Jewish World Service	90	$1,984,369		$ 1,984,369
amfAR, Foundation for AIDS Research	12	$950,122		$950,122
Andersen Foundation, Hugh J.	3	$29,000		$29,000
Andrus Family Fund	4	$256,000		$256,000
Annenberg Foundation	1		$12,500	$12,500
Anonymous Donors	51.5	$13,070,000	$2,500,000	$ 15,570,000

FOUNDATION NAME	Total Grants	Direct Grant Dollars	Regranting Dollars	Total Dollars
Anschutz Family Foundation, The	2	$12,500		$12,500
Anschutz Foundation, The	1	$ 5,000		$ 5,000
Appalachian Community Fund	3	$51,200		$51,200
Arabella Advisors	1	$ 2,500		$ 2,500
Arcus Foundation	147	$13,434,755	$3,572,000	$17,006,755
ARIA Foundation	8	$319,989		$319,989
Arizona Community Foundation	63	$658,276		$658,276
Asian Americans/Pacific Islanders in Philanthropy (AAPIP)	26	$60,000	$10,000	$70,000
Astraea Lesbian Foundation for Justice	246	$5,168,495		$5,168,495
AT&T Foundation	1	$10,000		$10,000
Auchincloss Foundation, Lily	1	$60,000		$60,000
Babson Charitable Foundation, Susan A. and Donald P.	10	$38,624		$38,624
Babson Foundation, Paul and Edith	5	$27,000		$27,000
Bank of America Charitable Foundation	44	$289,488		$289,488
Baron & Blue Foundation	1	$15,000		$15,000
Barr Foundation	1	$225,000		$225,000
Barra Foundation, The	2	$100,000		$100,000
Bastian Foundation, B. W.	46	$625,070		$625,070
Bernstein Memorial Foundation, Morey	1	$ 3,000		$ 3,000
Black Tie Dinner	20	$1,154,999		$1,154,999
Blandin Foundation	1	$180,000		$180,000
Blue Cross and Blue Shield of Minnesota Center for Prevention	1	$100,000		$100,000
Blue Shield of California Foundation	7	$227,000		$227,000
Bohnett Foundation, David	95	$1,392,981	$500	$1,393,481
Booth Ferris Foundation	2	$400,000		$400,000
Borealis Philanthropy	172	$3,181,800		$3,181,800
Boston Foundation	85	$610,050	$15,750	$625,800
Bread and Roses Community Fund	13	$72,376		$72,376
Bremer Foundation, Otto	7	$360,000		$360,000
Bristol-Myers Squibb Company	5	$33,500		$33,500
Broadway Cares/Equity Fights AIDS	58	$1,061,263		$1,061,263
Brother Help Thyself	34	$75,000		$75,000
Buffett Foundation, Susan Thompson	2	$300,000		$300,000
Bush Foundation	2	$110,000		$110,000
Cafritz Foundation, Morris and Gwendolyn	1	$42,400		$42,400
Calamus Foundation (Delaware)	15	$135,000	$50,000	$185,000
Calamus Foundation (New York)	16	$647,000		$647,000

FOUNDATION NAME	Total Grants	Direct Grant Dollars	Regranting Dollars	Total Dollars
California ChangeLawyers	1	$65,000		$65,000
California Community Foundation	116	$2,775,807	$3,000	$2,778,807
California Endowment, The	64	$3,780,111		$3,780,111
California Wellness Foundation	4	$815,000		$815,000
Calvin Klein Family Foundation	2		$20,000	$20,000
Campaign for Southern Equality	97	$53,151		$53,151
Campbell Foundation, The	5	$30,000		$30,000
CareOregon	4	$ 5,750		$ 5,750
Carmody Trust, The Kathrine C.	1	$10,000		$10,000
Casey Foundation, Annie E.	6	$87,500		$87,500
Casey Foundation, Marguerite	6	$822,500		$822,500
Celanese Foundation	1	$10,000		$10,000
Central Florida Foundation	18	$401,054	$ 5,000	$406,054
Chanin Foundation, Marcy and Leona	1	$ 2,000		$ 2,000
Charities Aid Foundation of America	1	$ 6,379		$ 6,379
Chernow Trust, Michael	1	$ 1,000		$ 1,000
Chicago Community Trust	2	$220,000		$220,000
Chicago Foundation for Women	5	$39,000		$39,000
Citi Foundation	1	$250,000		$250,000
Cleveland Foundation, The	13	$480,250		$480,250
Coca-Cola Foundation, The	3	$166,667		$166,667
COIL Foundation	5	$63,398		$63,398
Collins Foundation, The	7	$414,000		$414,000
Columbus Foundation	6	$42,799		$42,799
Comer Family Foundation	6	$32,000	$40,000	$72,000
Common Stream	2	$35,000		$35,000
Community Foundation for Greater Atlanta	1	$60,000		$60,000
Community Foundation for Northeast Florida	31.5	$515,900	$30,000	$545,900
Community Foundation for Southeast Michigan	30	$306,074		$306,074
Community Foundation for Southern Arizona	22	$66,835		$66,835
Community Foundation of Broward	15	$285,409	$200,411	$485,821
Community Foundation of Greater Birmingham	15	$110,580		$110,580
Community Foundation of Greater Fort Wayne	1	$ 2,420		$ 2,420
Community Foundation of Greater Greensboro	6	$123,703		$123,703
Community Foundation of Lorain County	1	$23,472		$23,472
Community Foundation of Louisville	2	$18,756		$18,756
Community Foundation of Middle Tennessee	4	$37,750	$45,000	$82,750
Community Foundation of Santa Cruz County	36	$128,850		$128,850

FOUNDATION NAME	Total Grants	Direct Grant Dollars	Regranting Dollars	Total Dollars
Community Foundation of Sarasota County	19	$126,188		$126,188
Community Foundation San Luis Obispo County	1	$ 5,000		$5,000
Community Foundation Serving Boulder County	35	$89,450		$89,450
Con Alma Health Foundation	1	$ 1,000		$1,000
Consumer Health Foundation	1	$30,000		$30,000
Core Health Foundation	1	$122,898		$122,898
Cream City Foundation	35	$123,500		$123,500
CREDO	1	$40,644		$40,644
Dallas Bears	1	$17,250		$17,250
Dallas Women's Foundation	1	$30,000		$30,000
DeCamp Foundation, Ira W.	2	$180,000		$180,000
deKay Foundation	1	$ 5,000		$5,000
Delaware Valley Legacy Fund	4	$ 9,600		$9,600
Design Industries Foundation Fighting AIDS (DIFFA)	15	$185,500		$185,500
District of Columbia Bar Foundation	1	$75,000		$75,000
Dollgener Memorial AIDS Fund, Greg	1	$ 1,000		$1,000
Doris Duke Charitable Foundation	2	$200,000		$200,000
Dwight Stuart Youth Fund	9	$226,000		$226,000
Dyson Foundation	4	$99,500		$99,500
Elizabeth Taylor AIDS Foundation	13	$144,700		$144,700
Elton John AIDS Foundation	74	$4,891,500	$75,000	$4,966,500
Esmond Harmsworth 1997 Charitable Foundation	9	$335,000		$335,000
Fels Fund, Samuel S.	3	$100,000		$100,000
Ford Foundation	32	$11,935,000	$510,000	$12,445,000
Foundation for a Just Society	13	$4,200,000	$440,000	$4,640,000
Foundation for Healthy St. Petersburg	3	$57,000		$57,000
Foundation for Louisiana	4	$79,500		$79,500
Foundation for the Carolinas - Charlotte Lesbian and Gay Fund	4	$45,300		$45,300
Fox Family Foundation, Frieda C.	1	$ 1,000		$1,000
Frameline	14	$36,817		$36,817
Freeman Foundation	14	$271,000	$65,000	$336,000
Fry Foundation, Lloyd A.	3	$105,000		$105,000
FSG	1	$ 2,500		$2,500
Fund For Global Human Rights	34	$482,466		$482,466
Funders for LGBTQ Issues	13	$235,000	$270,000	$505,000
Gamma Mu Foundation	37	$165,700		$165,700
Gates Foundation, Bill and Melinda	1	$15,000		$15,000

FOUNDATION NAME	Total Grants	Direct Grant Dollars	Regranting Dollars	Total Dollars
Gay Asian Pacific Alliance (GAPA) Foundation	13	$29,135		$29,135
GE Company	1	$10,000		$10,000
Geffen Foundation, David	1	$25,000		$25,000
Gerbic Family Foundation, Edward and Verna	1	$1,000		$1,000
Gilead Sciences	101	$8,930,648	$2,800,000	$11,730,648
Gill Foundation	80	$9,120,007	$400,000	$9,520,007
Gilmour-Jirgens Fund	1	$1,000		$1,000
GLMA: Health Professionals Advancing LGBT Equality	3	$50,005		$50,005
Global Fund for Women	23	$454,700		$454,700
Google	1	$1,000,000		$1,000,000
Grand Foundation, Richard	2	$35,000		$35,000
Grand Rapids Community Foundation	14	$83,000		$83,000
Grant Foundation, William T.	1	$25,000		$25,000
Grants for the Arts/San Francisco Hotel Tax Fund	17	$484,800		$484,800
Greater Barrington Foundation	1	$20,000		$20,000
Greater Kansas City Community Foundation	5	$1,203,950	$200,800	$1,404,750
Greater Milwaukee Foundation	2	$26,000		$26,000
Greater New Orleans Foundation	18	$95,722		$95,722
Greater Seattle Business Association	45	$350,000		$350,000
Greater Twin Cities United Way	2	$120,000		$120,000
Groundswell Fund	38	$1,126,554	$45,000	$1,171,554
Guilford Green Foundation	2	$20,000		$20,000
Gund Foundation, George	3	$250,000		$250,000
Haas Fund, Walter and Elise	5	$245,000		$245,000
Haas Jr. Fund, Evelyn and Walter	69	$5,038,200		$5,038,200
Hagedorn Fund	1	$30,000		$30,000
Haring Foundation, Keith	15	$380,000		$380,000
Harter Charitable Trust, John Burton	5	$87,500		$87,500
Hartford Foundation for Public Giving	10	$87,500		$87,500
Hayden Foundation, Charles	1	$100,000		$100,000
Hazen Foundation, Edward W.	2	$29,000		$29,000
Headwaters Fund for Justice	2	$34,000		$34,000
Health Foundation of Greater Indianapolis	1	$20,000		$20,000
Heinz Endowments, The	1	$13,050		$13,050
Hersh Foundation	1	$ 5,000		$ 5,000
Hewlett Foundation, William and Flora	9	$1,125,000		$1,125,000
Higginson Trust, Corina	1	$10,000		$10,000
Hill-Snowdon Foundation	2	$60,000		$60,000

FOUNDATION NAME	Total Grants	Direct Grant Dollars	Regranting Dollars	Total Dollars
Hoblitzelle Foundation	1	$54,315		$54,315
Hofmann Foundation, Kent Richard	2	$9,166		$9,166
Horizons Foundation	324	$1,632,479	$12,500	$1,644,979
Hormel Trust, James	1	$60,000		$60,000
Horwitz Foundation, Redlich	1	$25,000		$25,000
Human Rights Campaign	15	$180,850		$180,850
Hunt Foundation, Roy A.	1	$5,000		$5,000
Hyde and Watson Foundation	1	$15,000		$15,000
International Trans Fund	29	$500,000		$500,000
Intuit Foundation	15	$17,011		$17,011
Irvine Foundation, James	1	$50,000		$50,000
James Charitable Endowment Fund, Raymond	1	$5,000		$5,000
Jewish Communal Fund of New York	15	$906,917		$906,917
Jewish Community Federation of San Francisco, The Peninsula, Marin and Sonoma	4	$134,500		$134,500
Johnson & Johnson Family of Companies	1	$25,000	$100,000	$125,000
Johnson Family Foundation	30	$748,200	$50,000	$798,200
Johnson Foundation, Robert Wood	6	$71,800		$71,800
Junior League of Dallas	1	$5,000		$5,000
Just Fund Kentucky	18	$42,208		$42,208
Kaiser Permanente	4	$91,000		$91,000
Kalamazoo Community Foundation	1	$30,000		$30,000
Keith Founation Trust, Ben E.	2	$ 2,600		$ 2,600
Kellett Foundation, John Steven	6	$18,900		$18,900
Kerr Foundation, William A.	5	$67,500		$67,500
King Cole, Inc.	1		$19,500	$19,500
Knight Family Foundation	1		$37,500	$37,500
Knistrom Foundation, Fanny and Svante	1	$5,000		$5,000
Koffman, Betsy and Bates, Lorraine Family Fund	1	$25,000		$25,000
Kors Le Pere Foundation	1	$105,336		$105,336
LA84 Foundation	1	$2,500		$2,500
Langeloth Foundation, Jacob and Valeria	1	$2,500		$2,500
Larsen Foundation, John	4	$85,000		$85,000
Laughing Gull Foundation	6	$105,000	$50,000	$155,000
Leeway Foundation	14	$82,500		$82,500
Legg Mason Charitable Foundation	1	$700		$700
Levi Strauss Foundation	12	$1,045,500		$ 1,045,500
Liberty Hill Foundation	60	$604,960		$604,960

FOUNDATION NAME	Total Grants	Direct Grant Dollars	Regranting Dollars	Total Dollars
Lightner Sams Foundation	1	$15,000		$15,000
M.A.C. AIDS Fund	85	$4,803,389	$160,000	$4,963,389
MacArthur Foundation, John D and Catherine T.	5	$1,425,000		$ 1,425,000
Maine Community Foundation	8	$121,600		$121,600
Maine Health Access Foundation	3	$22,000		$22,000
Maine Women's Fund	2	$3,000		$3,000
Mandel, Amy and Rodis, Katina Fund	37	$1,037,710	$147,500	$1,185,210
Marguerite Casey Foundation	1	$7,500		$7,500
Marks Foundation, Carl	1	$1,000		$1,000
Masto Foundation	6	$15,500	$40,000	$55,500
McCarthy Foundation, Brian A.	7	$305,000		$305,000
McDermott Foundation, Eugene	1	$5,000		$5,000
McGregor Fund	2	$385,000		$385,000
McKenzie River Gathering	1	$10,000		$10,000
Mellon Foundation, Andrew W.	1	$1,159,000		$1,159,000
MetLife Foundation	9	$162,265		$162,265
Meyer Memorial Trust	14	$955,856		$955,856
Miami Foundation	46	$360,675		$360,675
Michaels Foundation, Howard and Jennifer	1		$6,250	$6,250
Miller Foundation, Herman and Frieda L.	1	$50,000		$50,000
Minneapolis Foundation	44	$89,394	$14,778	$104,172
Mirapaul Foundation	1		$12,500	$12,500
Missouri Foundation for Health	1	$209,688		$209,688
Moody Foundation	1	$20,000		$20,000
Moonwalk Fund, Silva Watson	14	$230,000		$230,000
Moriah Fund	2	$70,000		$70,000
Morrison and Foerster Foundation	11	$70,135		$70,135
Ms. Foundation for Women	3	$75,311		$75,311
Mukti Fund	3	$96,000	$1,000	$97,000
NEO Philanthropy	18	$1,319,985		$1,319,985
New York Community Trust, The	20	$803,250	$12,000	$815,250
New York Women's Foundation	19	$959,500		$959,500
New Yorkers for Children	1	$30,000		$30,000
Newpol Foundation	3	$35,000	$1,250	$36,250
Nordson Corporation Foundation, The	1	$13,000		$13,000
Nordstrom	1	$10,000		$10,000
Norris Preyer Fund, Marry	1	$5,000		$5,000
North Star Fund	21	$201,750		$201,750

FOUNDATION NAME	Total Grants	Direct Grant Dollars	Regranting Dollars	Total Dollars
Northrop Grumman	1	$2,500		$2,500
Northwest Area Foundation	4	$65,000	$60,000	$125,000
NoVo Foundation	7	$597,500	$165,000	$762,500
Ohio Transformation Fund	1	$40,000		$40,000
Omomuki Foundation	4	$25,940	$12,122	$38,062
Open Society Foundations	92	$7,577,998	$191,600	$ 7,769,598
Oregon Community Foundation	51	$341,983	$500	$342,483
Orlando City Soccer Club Foundation	2	$50,000		$50,000
Our Fund	236	$687,207	$51,000	$738,207
Our Fund - Contigo Fund	26	$614,824		$614,824
OUT Miami Foundation	5	$39,000		$39,000
Overbrook Foundation, The	14	$606,000	$155,000	$761,000
Packard Foundation, David and Lucile	1	$50,000		$50,000
Palette Fund	24	$1,114,325		$1,114,325
Parsons Foundation, Bob and Renee	1	$275,000		$275,000
Parsons Foundation, Ralph M.	1	$35,000		$35,000
Peace Development Fund	3	$132,431		$132,431
Pfund Foundation	33	$62,900		$62,900
Philadelphia Foundation	35	$347,252		$347,252
Pittsburgh Foundation, The	1	$10,000		$10,000
Point Foundation	97	$818,668		$818,668
Polk Bros. Foundation	6	$243,500		$243,500
Pride Foundation	348	$1,200,468		$1,200,468
Proteus Fund	9	$905,000		$905,000
Reynolds Babcock Foundation, Mary	1	$150,000		$150,000
Reynolds Foundation, Z. Smith	3	$105,000		$105,000
Richardson Fund, Anne S.	1	$30,000		$30,000
Richmond Memorial Health Foundation	2	$22,500		$22,500
Roaring Fork Gay and Lesbian Community Fund	1	$5,000		$5,000
Robin Hood Foundation	7	$1,109,500		$ 1,109,500
Roblee Foundation, Joseph H. and Florence A.	3	$50,000		$50,000
Rochester Area Community Foundation	14	$40,700		$40,700
Rockefeller Brothers Fund	1	$25,000		$25,000
Rockefeller Foundation	3	$300,000		$300,000
Rockefeller Philanthropy Advisors	1	$500		$500
Rohr Foundation, Mark & Rachel	1	$10,000		$10,000
Rolland Foundation, Ian and Mimi	1	$12,500		$12,500
Rorie Foundation, Ryan	1	$1,000		$1,000

FOUNDATION NAME	Total Grants	Direct Grant Dollars	Regranting Dollars	Total Dollars
Rosenberg Foundation	1	$750		$750
Rubin Foundation, Shelley and Donald	2	$30,000		$30,000
Rudin Family Foundation, May and Samuel	2	$75,000		$75,000
Samsara Foundation	1	$7,000		$7,000
San Diego Foundation	2	$36,350		$36,350
San Diego Human Dignity Foundation	18	$92,200	$300	$92,500
San Diego Pride	1	$6,000		$6,000
San Francisco Foundation	11	$186,857		$186,857
Santa Fe Community Foundation	22	$72,050		$72,050
Schott Foundation for Public Education	4	$105,000		$105,000
Seattle Foundation, The	5	$36,500		$36,500
Silicon Valley Community Foundation	10	$936,112		$936,112
Simmons Foundation, The	7	$240,000		$240,000
Skolnick Family Charitable Trust, The	1	$1,000		$1,000
Small Change Foundation	21	$501,000		$501,000
Snowdon Foundation, Ted	10	$277,000	$35,000	$312,000
Snyder Fund, Valentine Perry	2	$100,000		$100,000
Social Justice Fund Northwest	19	$183,906		$183,906
Southern Vision Alliance	5	$3,750		$3,750
Southwest Florida Community Foundation	1	$18,000		$18,000
Spartanburg County Foundation	5	$46,500		$46,500
Stonewall Community Foundation	142	$494,133		$494,133
Storr Family Foundation, The	1	$5,000		$5,000
Strengthen Orlando - OneOrlando Fund	302	$2,106,526		$2,106,526
Surdna Foundation	8	$66,100		$66,100
Tawani Foundation	18	$1,648,000		$ 1,648,000
TEGNA Foundation	1	$5,000		$5,000
Texas Pride Impact Funds	1	$11,000		$11,000
The LGBTQ Focus Foundation	5	$140,500		$140,500
Third Wave Fund	39	$391,800		$391,800
Tides Foundation	180	$7,524,762	$72,000	$ 7,596,762
TJX Foundation, The	6	$70,000		$70,000
Tov Adama Foundation	1	$2,500		$2,500
Trans Justice Funding Project	154	$500,500		$500,500
TurningPoint Foundation	1	$50,000		$50,000
Unitarian Universalist Program Veatch Program at Shelter Rock	7	$260,000	$70,000	$330,000
Unitarian Universalist Service Committee	4	$105,000		$105,000

FOUNDATION NAME	Total Grants	Direct Grant Dollars	Regranting Dollars	Total Dollars
United Way of Cleveland	1	$7,767		$7,767
United Way of Greater Cincinnati	1	$32,000		$32,000
United Way of Greater St. Louis	1		$60,000	$60,000
United Way of Metro Dallas	2	$180,000		$180,000
United Way of Tucson and Southern Arizona	1	$8,616		$8,616
Urgent Action Fund	38	$127,066		$127,066
van Ameringen Foundation, H	86	$4,349,500		$4,349,500
Vermont Community Foundation	23	$47,550	$36,000	$83,550.00
ViiV Healthcare	39	$2,742,325	$240,000	$2,982,325
Wallis Foundation	1	$5,000		$5,000
Warhol Foundation for the Visual Arts, Andy	2	$20,000		$20,000
Washington AIDS Partnership	5	$198,500		$198,500
Washington Area Women's Foundation	1	$500		$500
Washington Forrest Foundation	1	$3,000		$3,000
Weinberg Foundation, Harry and Jeanette	1	$200,000		$200,000
Wells Fargo	161	$3,339,971		$ 3,339,971
Wild Geese Foundation	21	$246,600		$246,600
Women's Foundation of California, The	11	$235,000		$235,000
Women's Foundation of Minnesota	1	$8,500		$8,500
Zarrow Family Foundation, Maxine & Jack	3	$4,000		$4,000
Zarrow Family Foundations	2	$6,500		$6,500
Zarrow Foundation, Anne and Henry	2	$45,000		$45,000
Zarrow Family Foundation, Maxine & Jack	1	$1,500		$1,500
Zarrow Foundation, Anne and Henry	2	$155,000		$155,000
Total	**6,297**	**$185,841,930**	**$13,087,261**	**$198,929,192**

METHODOLOGY & ACKNOWLEDGMENTS

METHODOLOGY

We surveyed the 2017 grantmaking activity of nearly 1,000 philanthropic entities in search of LGBTQ funding. All types of foundations were surveyed—private, public, community and corporate—as well as nonprofit organizations with grantmaking programs. Information was obtained predominantly through self-reporting by grantmakers, as well as through a review of 990s and annual reports. This report includes all information received as of December 20, 2018.

Our overarching research goal was to ensure that the data we collected focused specifically on LGBTQ issues and organizations. Therefore, the data set does not include grants to organizations or projects that are generally inclusive of LGBTQ people unless they explicitly address an LGBTQ issue or population. For example, a women's organization awarded a grant to develop a sex education curriculum for girls, open and welcoming to all girls, including LBTQ girls, would not have been included in the data. If that same organization was funded to provide sex education specifically to LBTQ girls, it would have been included.

We have included all re-granting dollars in charts that rank individual grantmakers and in the appendix to accurately show the overall level of LGBTQ funding provided by each grantmaker, regardless of whether those dollars are provided in the form of direct grants or through an intermediary that then re-grants those dollars to other organizations and individuals. As a result, the charts that rank grantmakers and the appendix "double-count" re-granting when aggregated. However, for all other tabulations and charts, we have not included dollars awarded for the purpose of re-granting, so as to avoid double counting.

ACKNOWLEDGMENTS

None of this work would be possible without our members and the other philanthropic entities who generously shared data on their grantmaking for LGBTQ communities. We are especially appreciative to our friends at Funders Concerned About AIDS (FCAA)—John Barnes, Sarah Hamilton, and Caterina Gironda—for sharing their LGBTQ-specific HIV/AIDS grantmaking data and for consistently being outstanding collaborative partners in our research efforts.

MISSION

Funders for LGBTQ Issues works to increase the scale and impact of philanthropic resources aimed at enhancing the well-being of lesbian, gay, bisexual, transgender and queer communities, promoting equity and advancing racial, economic and gender justice.

BOARD OF DIRECTORS

STAFF

REPORT CREDITS

Authors
Lyle Matthew Kan, Ben Francisco Maulbeck, and Andrew Wallace

Copy Editor
Alexander Lee

Creative Director
Andrew Wallace

Graphic Designer
Gabriel Lee (original design);
Trevor Messersmith, 80east Design (2017 Edition)

Lead Researcher
Andrew Wallace

Researchers
Eames Armstrong, Lyle Matthew Kan, Sarah Neddo, and Demian Yoon

45 West 36th Street, 8th Floor, New York, NY 10018 (212) 475-2930 (212) 475-2532
lgbtfunders.org @lgbtfunders facebook.com/LGBTQFunders