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March 13, 2024

The Honorable Robert Aderholt
Chair
Subcommittee on Labor, Health and
Human Services, Education, and
Related Agencies
U.S. House of Representatives
Washington, DC 20515

The Honorable Tammy Baldwin
Chair
Subcommittee on Labor, Health and
Human Services, Education, and
Related Agencies
U.S. Senate
Washington, DC 20510

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, Health and
Human Services, Education and
Related Agencies
U.S. House of Representatives
Washington, DC 20515

The Honorable Shelley Moore Capito
Ranking Member
Subcommittee on Labor, Health and
Human Services, Education, and
Related Agencies
U.S. Senate
Washington, DC 20510

***Double the Funding for the Department of Health and Human Services'
Office for Civil Rights***

Dear Chair Aderholt, Ranking Member DeLauro, Chair Baldwin, and Ranking Member Capito,

On behalf of The Leadership Conference on Civil and Human Rights, its Health Care Task Force, and the 132 undersigned organizations, we urge you to double the funding for the U.S. Department of Health and Human Services' (HHS) Office for Civil Rights (OCR). The Leadership Conference, a coalition of more than 240 national organizations, and its Health Care Task Force work to promote and protect the civil rights and health of all persons in the United States.

Health care is a civil and human right, and our health care system must ensure that the needs of individuals who are low-income, underserved, and face discrimination have access to resources to prevent and receive recourse against discrimination, and ensure the protection and security of private health information. Doubling the funding would increase OCR's budget from the current appropriated level of \$40 million to \$80 million in FY2025 appropriations. This vital office is imperative to the function of the department as a whole, and has been inadequately funded for far too long. Considering the incredible breadth of responsibility of the office and the increasingly urgent demands on it as our health care system continues to evolve, Congress must appropriate the funds necessary for the office to effectively and efficiently do its job.

The Office for Civil Rights is HHS's primary enforcement and regulatory agency of civil rights and health information privacy and security. HHS OCR has a unique responsibility to engage in outreach, education, implementation, and enforcement around the core civil rights and privacy laws and their application in health care settings. To carry out its functions, OCR investigates complaints, enforces the law, develops policy, promulgates regulations, and provides technical assistance and public education to ensure understanding of, and compliance with, these laws. At its core, OCR works to ensure that people receiving services from HHS-conducted or HHS-funded programs are not subject to discrimination, and that they can trust the privacy, security, and availability of their health information.

OCR's responsibilities have considerable impact on the health and well-being of people across the country. Doubling the funding for OCR in FY2025 appropriations will allow the office to bolster its efforts in all nondiscrimination areas, including race, ethnicity, national origin (including language), age, sex (including sex stereotypes; sex characteristics, including intersex traits; pregnancy or related conditions, including termination of pregnancy; sexual orientation; and gender identity), and disability, as well as its work to secure personal health information under the Health Insurance and Portability Accountability Act (HIPAA). This work is essential for promoting equity in health care settings for people who have historically faced discrimination and for protecting individuals' privacy.

OCR enforces 55 different privacy, security, civil rights, and religious freedom statutes, including Section 1557 of the Affordable Care Act (ACA); Section 504 of the Rehabilitation Act of 1973; Title VI of the Civil Rights Act of 1964; the Age Discrimination Act of 1975; HIPAA Privacy, Security, and Breach Notification Rules; and the Patient Safety Act and Rule. These laws protect fundamental rights of nondiscrimination and health information privacy, and were enacted in recognition of the potential for discrimination and breach of privacy in health care settings.

Although progress has been made in the years since many of these civil rights laws were enacted, they continue to serve a vital function in the face of ongoing discrimination. Robust enforcement of Section 1557, the nondiscrimination provision of the ACA, is a particular area of concern for our groups, as many of the communities we represent rely upon the law to provide protection from discrimination. Given the pervasive legacy of discrimination in health care and health systems, Section 1557 has represented a significant step toward rectifying centuries of policies and practices that have created worse health outcomes for communities of color, people with disabilities, women, LGBTQ+ people, Limited English Proficient (LEP) individuals, older adults and children, and other systemically underserved groups. As we wait for the release of the Biden administration's final Section 1557 rule, we anticipate the department will need additional resources to engage in education and enforcement in communities. The proliferation of racist, sexist, ableist, and anti-LGBTQ+ policies across the country make OCR's mandate to vigorously enforce civil rights laws more urgent now than ever. Federal antidiscrimination laws are critical tools, especially in today's climate, and OCR must be provided the necessary resources to meet the moment.

Unfortunately, discrimination in health care is a pervasive issue, and OCR has a substantial backlog of complaints that have gone unaddressed because of its lack of staff and resources over the years. In fact,

since FY2016, civil rights case receipts have increased by 252 percent.¹ Despite this, OCR's enforcement staff has actually decreased by 45 percent due to flat budgets and inflationary increases. Increased funding would allow OCR to hire additional staff to help address this backlog, affording the opportunity for a full investigative process. Additionally, increased funding would allow the office to initiate compliance reviews in the administration's priority areas, and allocate appropriate staffing to regional offices so that complaints are responded to in a timely, meaningful, and equitable way.

Regulation and guidance are also critical tools that help to prevent unlawful discrimination from occurring in the first place. HHS is charged with issuing clarifying civil rights policy guidance and regulations to implement the laws under its jurisdiction and to provide other technical assistance to covered entities and providers to help meet their obligations to patients. This policy work must be informed by extensive engagement and collaboration with stakeholders, especially marginalized communities, and those who advocate with and for them. OCR must have the necessary resources to provide training and technical assistance to ensure that laws are implemented effectively and individuals are served equitably. Robust technical assistance from OCR must be available to empower all covered entities and providers to prevent and challenge discrimination, including while investigations are pending. Our communities deserve both words and actions by HHS and OCR that respond to their concerns, protect their rights, and follow the law.

Similarly, OCR must also pursue proactive compliance reviews to ensure federally funded programs are not discriminating even in instances where complaints have not yet been filed. The communities with and for whom we work deserve to have OCR firmly uphold the laws that protect them from discrimination, and all taxpayers deserve the reassurance that federal funds are not being used to discriminate. OCR needs robust funding and sufficient staff to ensure that individuals are supported by a department that will not tolerate discrimination and that will work to ensure access to justice for all. Increased funding would enable OCR to engage in outreach and education that could reduce discrimination and make filing complaints less necessary.

In addition to its mandate to address discrimination, OCR is charged with administration and enforcement of the HIPAA Privacy, Security, and Breach Notification Rules (HIPAA Rules). OCR must ensure that covered entities understand and comply with the HIPAA Rules; increase patient awareness and exercise of their HIPAA rights and protections; and facilitate coordination of care through appropriate information sharing. These responsibilities are particularly staggering given the sharp increase in HIPAA complaints over the years: since FY 2017, OCR has received a 28 percent increase in HIPAA complaints, and a 100 percent increase in HIPAA large breach reports.² These developments highlight the need for additional funding so that OCR may invest in staff that can help address this growing backlog of complaints and ensure that private health information is protected.

Despite its considerable responsibilities, OCR's budget has remained flat for many years, changing only slightly with inflation. The stagnant budget has resulted in resources and staff that, despite the office's

¹ See HHS FY 2024 Budget in Brief, available at <https://www.hhs.gov/sites/default/files/fy-2024-budget-in-brief.pdf>.

² *Id.*

best efforts, have become increasingly strained. For more than 20 years, a flat budget has prevented OCR from being able to modernize its infrastructure. Although the office does the best it can with the resources it has, we also recognize the near impossibility of its charge to fulfill its enforcement, technical assistance, and outreach duties with such a limited budget. We believe implementation and enforcement of civil rights statutes is important across the entire federal government, and that all offices for civil rights should be adequately funded. However, HHS OCR is often left behind in comparison with the funding and resources allocated to other offices for civil rights across departments, and must be appropriately funded in order to fulfill its vast responsibilities. FY2025 appropriations must provide robust funding for OCR to ensure that the office, as well as HHS overall, can carry out its most essential duties.

We urge you to double the funding for the Office for Civil Rights to ensure that the Department of Health and Human Services is able to fulfill its responsibility to protect the civil rights of all people. Thank you for your consideration of our views. For more information, please contact Leadership Conference Health Care Task Force co-chair Mara Youdelman, National Health Law Program (youdelman@healthlaw.org), or Leadership Conference Policy Counsel Peggy Ramin (ramin@civilrights.org).

Sincerely,

The Leadership Conference on Civil and Human Rights
National Health Law Program, Health Care Task Force Co-Chair
National Partnership for Women & Families, Health Care Task Force Co-Chair
ACA Consumer Advocacy
ACCESS REPRODUCTIVE JUSTICE
Advocates for Youth
American Atheists
American Humanist Association
Arkansas Black Gay Men's Forum
Asian & Pacific Islander American Health Forum
Asian Pacific Institute on Gender-Based Violence
Assistive Technology Law Center
Association of Asian Pacific Community Health Organizations (AAPCHO)
Association of Maternal & Child Health Programs
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Bazelon Center for Mental Health Law
Bend the Arc: Jewish Action
California Pan-Ethnic Health Network
Center for Elder Law & Justice
Center for Law and Social Policy (CLASP)
CenterLink: The Community of LGBTQ Centers
Choose Healthy Life
Clearinghouse on Women's Issues
Colorado Consumer Health Initiative

CommunicationFIRST
Community Catalyst
Disability Law Center of Utah
Disability Law Center, Inc.
Disability Policy Consortium
Disability Rights California
Disability Rights Education and Defense Fund (DREDF)
Disability Rights Oregon
Disability Rights Washington
Drug Policy Alliance
Equality California
Families USA
Family Voices
Family Voices NJ
Family Voices of Tennessee
Feminist Majority Foundation
First Focus Campaign for Children
Futures Without Violence
Georgians for a Healthy Future
GLMA: Health Professionals Advancing LGBTQ+ Equality
Guttmacher Institute
Hadassah, The Women's Zionist Organization of America
Haitian Bridge Alliance
Hawai'i Health & Harm Reduction Center
Hepatitis B Foundation
HIV + Hepatitis Policy Institute
Human Rights Campaign
Impact Fund
In Our Own Voice: National Black Women's Reproductive Justice Agenda
Ipas
Japanese American Citizens League (JACL)
Jewish Council for Public Affairs
Justice in Aging
JustLeadership USA
Kentucky Health Justice Network
Latino Commission on AIDS
Lawyers for Good Government
League of Women Voters of the United States
Legal Action Center
Los Angeles LGBT Center
Mississippi Center for Justice
Missouri Asian American Youth Foundation
Movement Advancement Project

NAACP

National Abortion Federation

National Asian American Pacific Islander Mental Health Association (NAAPIMHA)

National Asian Pacific American Women's Forum

National Association of Certified Professional Midwives

National Association of Councils on Developmental Disabilities

National Association of Pediatric Nurse Practitioners

National Association of Social Workers

National Black Justice Coalition

National Center for Lesbian Rights

National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)

National Council of Jewish Women

National Disability Rights Network (NDRN)

National Employment Law Project

National Health Care for the Homeless Council

National Hispanic Media Coalition

National Immigration Law Center

National Latina Institute for Reproductive Justice

National League for Nursing

National LGBTQ Institute on Intimate Partner Violence

National Network for Arab American Communities (NNAAC)

National Partnership for New Americans

National Women's Health Network

National Youth Employment Coalition

North Dakota Protection and Advocacy Project

OCA - Asian Pacific American Advocates

Parents Reaching Out

People Power United

Physicians for Reproductive Health

Poverty Project at the Institute for Policy Studies

Protect Our Care

Public Advocacy for Kids (PAK)

Public Justice Center

Reproaction

Reproductive Freedom for All (formerly NARAL Pro-Choice America)

Reproductive Health Impact: The Collaborative for Equity and Justice

RootsAction.org

Safe States Alliance

SEIU

SIECUS: Sex Ed for Social Change

Silver State Equality

South Asian Public Health Association

SPAN Parent Advocacy Network

SPLC Action
State Innovation Exchange (SIX)
The AIDS Institute
The Arc of the United States
The Coelho Center for Disability Law, Policy and Innovation
The Fenway Institute
The Legal Aid Justice Center
The Parents' Place of MD
The Praxis Project
The Pride Center at Equality Park
The Secular Coalition for America
The University of Baltimore's Center on Applied Feminism
Transhealth
True Colors United
U.S. Gender and Disability Justice Alliance
UnidosUS
United Spinal Association
United Steelworkers
Voices for Progress
Whitman-Walker Institute
William E. Morris Institute for Justice
Young Center for Immigrant Children's Rights