The Leadership Conference
on Civil and Human Rights

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May 12, 2025

The Honorable Robert F. Kennedy Jr.
Secretary
U.S. Department of Health and Human Services
200 Independence Ave., SW
Washington, DC 20201

Dear Secretary Kennedy:

The Leadership Conference on Civil and Human Rights is the nation's oldest, largest, and most diverse civil and human rights coalition, charged by its membership of more than 240 national organizations to promote and protect the civil and human rights of all people in the United States. Our coalition provides a powerful and unified voice for the many constituencies we represent, including communities of color, people with disabilities, women, LGBTQI+ people, immigrants, Limited English Proficient (LEP) individuals, older adults and children, people with low incomes, rural communities, and other systemically underserved groups. The undersigned organizations are united by the universal ideals of dignity, equity, justice, and inclusion. We believe that working together to protect, defend, and expand the rights of every person in the United States will in turn lead to a more open and just society — an America as good as its ideals.

The Leadership Conference's work is conducted primarily through our 11 task forces, which bring our members together around issues including health care, education, immigration, employment, and housing. Our Health Care Task Force is co-chaired by the National Health Law Program (NHeLP) and the National Partnership for Women & Families and is comprised of organizations who work to promote and protect the civil rights and health of all people in the United States. As members of the Health Care Task Force, we offer the following recommendations for the Department of Health and Human Services, which has a duty to fulfill the civil rights promise and intent of improving health care quality, access, affordability, and equity. The Leadership Conference and its Health Care Task Force intend to ensure that the department and all those tasked with the immense responsibility of enforcing our nation's civil rights laws and health care policies are held accountable to do exactly that.

Health care is a civil and human right. Our foundational civil rights laws, made meaningful through enforcement and oversight, stand guard to protect that right. Every human being in this country should be able to obtain timely, affordable, comprehensive, high-quality, and accessible health care. This includes access to the full scope of best-practice medical care for transgender people, as well as sexual and reproductive health services, including abortion.

Access to quality health care coverage and services should not be based on income, pre-existing conditions, health status, substance use or mental health history, immigration status, criminal record history, or geographic location, and barriers based on these issues must be removed. Race, ethnicity, national origin (including language), age (from birth through death), sex (including sex stereotypes; sex characteristics, including intersex traits; pregnancy or related conditions, including termination of pregnancy; sexual orientation; and gender identity), disability, religion, or employment status must not impede access to care. Further, for people to be able to truly access health care, they must have access to other supports, including paid leave, paid sick days, transportation, housing, and affordable child care.

We recognize that systemic issues prevent true health equity. Health inequities must be addressed as a matter of social justice, and also as an economic imperative; failure to address these inequities adds hundreds of billions of dollars to our country's health care spending each year.[1] Health care policies must dismantle barriers that exist due to entrenched and systemic sexism, racism, xenophobia, ableism, and discrimination against LGBTQI+ people and those with intersectional identities in the health care system. Health reforms must aim not only to reduce disparities, but also to ultimately eliminate disparities entirely. The department must also ensure that discrimination does not impede individuals from accessing health care and services. This requires robust implementation and enforcement of not just health care laws but also, importantly, civil rights laws across all entities throughout the health care system. Further, reforms should not allow the religious and/or personal beliefs of a hospital, clinic, insurance company, or provider to impede anyone's ability to make decisions about their health and receive the health care they need. Robust implementation also requires the collection, analysis, and use of health data to understand where disparities exist and whether and how policies are successfully addressing them. However, any data collected or shared about individuals or communities across the health care system must be kept confidential, in compliance with appropriate security protocols and confidentiality laws, used only for the express purpose for which it was collected, and not be used to discriminate against them. When data are used outside of the intended purpose for which they were collected or are not accurately deidentified, it can chill people from accessing services and contribute to declining response rates in necessary federal data collections, which in turn worsens outcomes and costs the system more money.

Health care coverage must be affordable for all people. This includes those who are underserved or have lower incomes or higher than average health care costs. Any burdens imposed on populations with lower incomes by premiums or cost-sharing requirements must be mitigated. Additionally, benefit design must not be discriminatory. Reforms must continue prohibitions on discriminatory health care benefit designs that could exclude or have a disparate impact on specific populations with higher health care costs or who are part of a protected class. This includes cost-sharing structures that disproportionately and discriminatorily affect individuals who have higher health care needs or require uncommon services or treatments.

[1] "Health inequities add $320 billion annually to health care spending in the United States, a figure that could surpass $1 trillion by 2040 if left unaddressed." *See* "Health equity remains a business imperative in the life sciences and health care industries," Deloitte Center for Health Solutions (Jan. 28, 2025), https://www2.deloitte.com/us/en/insights/industry/health-care/health-equity-business-imperative-in-2025.html.

Health care and long-term services and supports must be high quality, including being person-centered, responsive to cultural, social, behavioral, and linguistic needs, and allow individuals to receive the right care, at the right time, and in the setting best suited for their needs. This includes expanding access to appropriate supports and services, including home and community-based services (HCBS), that enable people to continue to live and thrive in their communities. High quality care and support requires engagement and collaboration with the people receiving care, their families and their caregivers, community-based organizations, and consumer advocacy organizations. High quality health care means that there should be no room for waiving any aspect of health care insurance or delivery in a manner that could adversely impact consumers and undermine minimum federal protections.

The department must address social drivers of health in all policy efforts and recognize that much of a person's health care outcomes result from factors outside of the health care setting and outside of their individual control. The delivery of health care must account for health impacts resulting from discriminatory laws, policies, and norms that have led to disparate outcomes due to differences in where people are born, live, learn, work, play, worship, and age. Reform efforts should incentivize providers and institutions to incorporate strategies that address social determinants of health in their care models. Such efforts should have health equity as an explicit goal, rely on multi-sector partnerships, and be person-centered. The department must acknowledge and address structural racism and other forms of discrimination that create and reinforce inequities; support and promote community partnerships; require robust and privacy-preserving data collection, analysis, and reporting; and leverage and build upon existing care delivery models and resources that offer promising opportunities to advance health equity.

The aforementioned principles are essential to the work our organizations do to advance civil rights and health equity. These values must guide every action the department takes to address access to health care for all and to improve the health care system. We expect the department to adhere to democratic tenets of transparency and accountability and to faithfully uphold the rule of law, including utilizing proper notice and comment in the rulemaking process. We are deeply concerned about recent actions taken by the administration to restructure and enact drastic cuts to the department, which will seriously jeopardize its ability to fulfill its promise to ensure the health and well-being of all people in this country. These actions not only undermine the effectiveness and efficiency of the department, but they have also put the private health information of individuals at risk and disrupted critical research, amounting to a wholesale assault on public health.

The elimination of the Administration for Community Living (ACL) and drastic cuts and changes made to the Substance Abuse and Mental Health Services Administration (SAMHSA) and Office for Civil Rights (OCR) raise serious concerns about the ability of the department to deliver on its obligation to ensure that everyone in this country can receive crucial health care, support, and services and can seek redress when they experience harm. Likewise, the elimination of all of the department's offices of minority health, tasked with the coordination of efforts to eliminate health disparities and improve the health of racial and ethnic minority populations, puts the health of these communities at even greater risk. Additionally, cutting tens of thousands of jobs across the Centers for Medicare & Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), Health Resources and Services Administration (HRSA), and Food and Drug Administration (FDA) has

implications for the ability of the department to adequately address public health needs, engage in oversight and investigations, and ensure access to health services. Most recently, the closure of CMS' Office of Equal Opportunity and Civil Rights calls into question its ability to comply with civil rights law and properly address claims of workplace harassment and discrimination.

As organizations dedicated to protecting and advancing civil rights in health care, we are particularly concerned about the impact of the reorganization on OCR. As you know, OCR is HHS's primary enforcement and regulatory agency of civil rights and health information privacy and security. OCR has a unique responsibility to engage in outreach, education, training, implementation, and enforcement around the core civil rights and privacy laws and their application in health care settings. At its core, OCR works to ensure that all 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, consistent with the laws of this nation. The reorganization, including the closing of half of HHS's regional offices, could severely impact the ability of people to seek recourse from discrimination and undermine OCR's ability to fulfill its civil rights obligations. OCR's budget has remained flat for many years, resulting in increasingly strained resources and staff and leading to a growing backlog of unaddressed complaints — a situation that will only be exacerbated by the recent cuts. Additionally, the reorganization could weaken OCR's ability to maintain and enforce privacy standards under HIPAA and 42 CFR Part 2, endangering the ability of people who require confidentiality in medical conditions to receive treatment without fear of retribution.

The undersigned organizations expect the department to be transparent about its actions and abide by requirements that allow for public participation in the federal rulemaking process. These requirements ensure the public has an opportunity to provide meaningful input as regulations that profoundly impact our health care are proposed or changed. We urge HHS to ensure that all of its proposed regulations are open for public comment and to appropriately consider all public input during the regulatory process. Our call for transparency and public input is particularly pressing as Medicaid faces unprecedented attacks, threatening health care access for people across the country. The 80 million people who receive their health care through this program deserve to have their voices heard about proposed changes that will impact their health and well-being. Our communities must not be relegated to bystanders as others determine how our health care is delivered.

We will not tolerate any attacks on access to our health care, including attacks against people of color, people with disabilities, women, LGBTQI+ people, immigrants, Limited English Proficient (LEP) individuals, older adults and children, people with low incomes, rural communities, and other underserved communities. We call for the department to uphold the core American tenets of equal opportunity, nondiscrimination, and diversity, as well as transparency and a respect for the rule of law. We hope that you will be guided by these values as you make decisions that will impact the health and civil rights of all people in the United States. The Leadership Conference and its Health Care Task Force stand ready to ensure that those who are tasked with faithfully enforcing our nation's civil rights laws and health care policies fulfill their mandate to do so.

If you have any questions, please contact The Leadership Conference Health Care Task Force through Peggy Ramin, senior policy counsel at The Leadership Conference on Civil and Human Rights at ramin@civilrights.org; Mara Youdelman, managing director of federal advocacy at the National Health Law Program at youdelman@nhelp.org; or Sarah Coombs, interim vice president and director for health system transformation at the National Partnership for Women & Families at scoombs@nationalpartnership.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
American Civil Liberties Union
American Federation of State, County and Municipal Employees (AFSCME)
Americans United for Separation of Church and State
APAPA National (Asian Pacific American Public Affairs Association)
Asian & Pacific Islander American Health Forum (APIAHF)
Asian American Psychological Association (AAPA)
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Center for Law and Social Policy (CLASP)
Center for Reproductive Rights
Community Catalyst
Disability Rights Education and Defense Fund (DREDF)
Empowering Pacific Islander Communities (EPIC)
Equality California
Families USA
Human Rights Campaign
The Institute for Health Research & Policy at Whitman-Walker
Japanese American Citizens League
Justice in Aging
Lawyers' Committee for Civil Rights Under Law
Legal Action Center
NAACP
National Abortion Federation
National Asian American Pacific Islander Mental Health Association
National Council of Asian Pacific Americans (NCAPA)
National Council of Jewish Women
National Education Association
National Immigration Law Center
National Latina Institute for Reproductive Justice
National Network for Arab American Communities (NNAAC)
Planned Parenthood Federation of America

Service Employees International Union (SEIU)
Southern Poverty Law Center
SPAN Parent Advocacy Network (SPAN)
UnidosUS