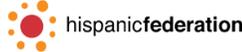


Civil Rights Principles for Health Reform



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To fulfill the civil rights promise and intent of improving health care quality, access, affordability, and equity, any next steps in reforming the U.S. health care system must ensure that the needs of individuals who are low-income, underserved individuals, and underserved communities are embedded in reforms from beginning to end. We stand united by the universal values of dignity, equity, justice, and inclusion. The Health Care Task Force of The Leadership Conference on Civil and Human Rights has developed the following principles to guide any next steps taken to improve access to health care for all and the health care system, noting that addressing health inequities is inextricably linked to ensuring coverage for all.

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OVERARCHING PRINCIPLES

1. Health care is a human right.
2. Systemic issues preventing health equity must be dismantled.
3. Individuals must not be discriminated against.
4. Health care coverage must be affordable for all people.
5. Benefit design must not be discriminatory.
6. Health care should be high quality and patient-centered.
7. Health reform must address social determinants of health.

SERVICES

8. Benefits must be comprehensive.
9. Coverage must ensure that people with disabilities are not served needlessly in segregated settings.
10. Health care must be accessible to all.
11. Prescription drugs must be affordable.
12. Reproductive and sexual health services must be comprehensive.

ENFORCEMENT

13. Individuals must be able to enforce their rights to access care.
14. Strong protections must be included and enforceable.
15. Transparency is critical to ensure informed decision making and identification of disparities.

ENROLLMENT, OUTREACH, DATA, and QUALITY

16. Reforms should include outreach funding and policies to encourage enrollment.
17. Health care entities must collect and report comprehensive data.
18. Other government health care programs must be equitable to any changes made.
19. Clinical practice guidelines and standards of care are important tools to promote high quality care and should be followed, but their limitations must be understood and remedied.
20. Ensure diversity in clinical research.

WORKFORCE

21. The health care workforce must be diverse and stable.
22. Education and training programs for health professionals must be accessible and affordable for all.
23. Training for health professionals must include issues related to bias, discrimination, and cultural competency.
24. Compensation for health care providers and professionals must be equitable.
25. Provider networks must be comprehensive.

FUNDING

26. The system must be well-financed.
27. Adequate resources and funding must be available to address health equity.

Signers of these principles as of July 16, 2019:

1. The Leadership Conference Education Fund
2. The Leadership Conference on Civil and Human Rights
3. National Health Law Program (NHeLP)
4. National Partnership for Women & Families
5. American-Arab Anti-Discrimination Committee (ADC)
6. American Arab Institute (AAI)
7. American Association of People with Disabilities (AAPD)
8. American Federation of Teachers (AFT)
9. Andrew Goodman Foundation
10. Asian & Pacific Islander American Health Forum (APIAHF)
11. Association of Asian Pacific Community Health Organizations (AAPCHO)
12. Association of University Centers on Disabilities (AUCD)
13. Autistic Self Advocacy Network (ASAN)
14. Bazelon Center for Mental Health Law
15. Center for Law and Social Policy (CLASP)
16. Center for Reproductive Rights (CRR)
17. Coalition for Disability Health Equity
18. Disability Rights Education & Defense Fund (DREDF)
19. Equal Justice Society (EJS)
20. Families USA
21. Feminist Majority
22. Hispanic Federation
23. Human Rights Campaign
24. Japanese American Citizens League (JACL)
25. Justice in Aging
26. NAACP
27. National Association of Human Rights Workers (NAHRW)
28. National Association of Social Workers (NASW)
29. National Center for Transgender Equality (NCTE)
30. National Coalition for Asian Pacific American Community Development (National CAPACD)
31. The National Coalition on Black Civic Participation
32. National Disability Rights Network (NDRN)
33. National Education Association (NEA)
34. National Fair Housing Alliance (NFHA)

35. National Hispanic Media Coalition (NHMC)
36. National Immigration Law Center
37. National Latina Institute for Reproductive Health
38. National LGBTQ Task Force
39. National Organization for Women (NOW)
40. National Urban League
41. National Women's Law Center (NWLC)
42. PFLAG National
43. Planned Parenthood Federation of America (PPFA)
44. Poverty & Race Research Action Council (PRRAC)
45. Service Employees International Union (SEIU)
46. Shriver Center on Poverty Law
47. TASH
48. U.S. International Council on Disabilities (USCID)
49. United Steelworkers (USW)
50. Voices for Progress
51. Voto Latino
52. YWCA USA

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To fulfill the civil rights promise and intent of improving health care quality, access, affordability, and equity, any next steps in reforming the U.S. health care system must ensure that the needs of individuals who are low-income, underserved individuals, and underserved communities are embedded in reforms from beginning to end. We stand united by the universal values of dignity, equity, justice, and inclusion. The Health Care Task Force of The Leadership Conference on Civil and Human Rights has developed the following principles to guide any next steps taken to improve access to health care for all and the health care system, noting that addressing health inequities is inextricably linked to ensuring coverage for all.

OVERARCHING PRINCIPLES

1. **Health care is a human right.** Every human being in the United States of America should be able to obtain timely, affordable, comprehensive, high-quality, and accessible health care. Race, ethnicity, national origin (including ethnic characteristics and immigration status), language, sex (including pregnancy and related medical conditions, termination of pregnancy, family status, sex characteristics, sex stereotypes, gender identity, and sexual orientation), class, disability, religion, age, or employment status must not be barriers to receiving health care. Health care access should not be based on income, pre-existing conditions, health status, immigration status, incarceration/detention, or geographic location, and barriers based on these issues must be removed. Every person should be able to safely access health care without fear of discrimination, harassment, persecution, criminal prosecution, or detention/arrest. Further, for people to be able to truly access health care, they must have access to other supports, including paid leave, paid sick days, and affordable child care.
2. **Systemic issues preventing health equity must be dismantled.** Policies must dismantle barriers that exist due to entrenched and systemic sexism, racism, xenophobia, and discrimination against people with disabilities and LGBTQ people in the healthcare system. Policies must also take into account that identities and experiences are intersectional; that is, individuals often do not belong to only one community or population group or another, but rather the multiple aspects of their identity lead to interconnected and potentially exacerbated oppressions. Reforms must aim not only to reduce disparities, but to ultimately eliminate disparities entirely. It is not enough for the health care system to produce improved results on average; it must produce meaningful results across populations and subpopulations. Further, measures intended to achieve health equity must do so without causing further harm to underserved communities.
3. **Individuals must not be discriminated against.** Reforms must ensure robust implementation and enforcement of civil rights laws across all entities throughout the health care system and ensure federal funds only go towards institutions that do not discriminate based on race, ethnicity, national origin (including ethnic characteristics and immigration status), language, sex (including pregnancy and related medical conditions, termination of pregnancy, family status, sex characteristics, sex stereotypes, gender identity, and sexual orientation), class, disability, religion, or age. 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. Finally, any data collected or shared about individuals or communities across the health care system must not be used to discriminate against them.

4. **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. Cost sharing must not create barriers to care or financial hardship or threaten anyone's ability to meet their basic needs. Any cost sharing requirements must provide protections for individuals who are low-income, people with disabilities, and those with chronic conditions and people requiring high cost treatments or services. Reform must also ensure affordability for people of all incomes in public and private programs. To the extent individuals are insured and limited to a network, surprise bills should be prohibited and out of network costs should be capped.
5. **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 of minority status. This includes cost-sharing structures that disproportionately and discriminatorily affect individuals who have higher health care needs or require uncommon services or treatments.
6. **Health care should be high quality and patient-centered.** Health care and long-term services and supports must be high quality, including being patient-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. High quality care and support is based on the principle of delivering the right care at the right time and requires engagement and collaboration with patients, families and their caregivers, community-based organizations, or 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. Reforms must also prohibit using Quality-Adjusted Life Years, Disability- Adjusted Life Years, and other comparative-effectiveness measures that devalue the lives, experiences, and perspectives of people with disabilities and chronic health conditions.
7. **Health reform must address social determinants of health.** Health reform must recognize that much of a person's health care outcomes result from factors outside of the health care setting. 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 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. Legislation should 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.

SERVICES

8. **Benefits must be comprehensive.** Individuals must have the opportunity to make all health care choices. No individual or group should have fewer benefits available under new proposals. Coverage must include, at a minimum, all essential health benefits defined in the Affordable Care Act (ACA), which should be defined at the federal level. All preventive services provided pursuant to the ACA must also be included. In addition to the specific services mentioned below, the following services must be included with a federally defined scope of benefits: non-emergency transportation; dental, vision, and hearing coverage; and EPSDT for all individuals up to age 21. Benefits should also include integrative and complementary medicine as a way of ensuring cultural competence. We oppose any restrictive eligibility requirements that would take away or create barriers to coverage, as well as any weakening of Medicaid's eligibility or benefit structure.

9. **Coverage must ensure that people with disabilities are not served needlessly in segregated settings.** Benefits coverage should not result in people with disabilities being needlessly segregated – for example, by failing to cover services that are essential for people with disabilities to live in their own homes or other integrated settings and covering services instead in segregated settings, or by covering a particular benefit in greater amounts to individuals in segregated settings. Long Term Supports and Services (LTSS) that include home and community-based services are critical to ensure that individuals can receive care in the setting they choose, and to protect the civil rights of individuals with disabilities and complex medical needs and older individuals. In addition to traditional health care services, provision for LTSS must be included to provide adequate support for the services individuals need to live and thrive. Priority must be placed on providing LTSS services in the community and allow for a continuum of care needs, such as when individuals need short inpatient stays to address changes in their health condition. In addition, an investment in the direct care workforce is needed to ensure a stable workforce is available to meet the demand for LTSS services. The “institutional bias” currently existing in Medicaid must be eliminated. Reimbursement rates should not result in needless segregation – for example, by setting reimbursement rates for services higher than rates for similar services in integrated settings.

10. **Health care must be accessible to all.** Any reform must include direct payments to providers and healthcare entities for communication assistance and other accommodations to ensure that all individuals, and particularly individuals with disabilities and individuals with limited English proficiency, can access health care services. These payments should enable providers to access qualified medical language interpreters but not create any incentives for providers to use bilingual unqualified staff or family members of patients. Direct payment must be provided for communication services, including but not limited to interpreting, ensuring accessibility of written documents (including paying for translation into foreign languages and creation of Braille/large print documents or audio/video alternatives), and providing auxiliary aids and services. Health providers must be accessible to people with disabilities. Health reform must ensure that people with disabilities can receive services from providers in accessible locations. Further, reimbursement should be provided for specialized equipment to ensure program access (e.g. accessible examination tables, physical lifts). The availability of funding for accessibility services in no way would limit an individual's rights under existing

civil rights laws. These services should be provided by entities and organizations that best meet the needs of patients.

11. **Prescription drugs must be affordable.** At a minimum, current Medicaid prescription drug affordability protections must be maintained and policies that harm access to necessary care, such as prior authorization, step therapy, and quantity limits should be narrowly implemented. Proposals should also address the high cost of prescription medications in a systemic way by identifying and tackling its root causes, and without placing the burden of bringing down costs on individuals with low incomes. This includes incorporating policies to promote drug innovations that address the health needs of underserved individuals and communities, rather than prioritizing the development of drugs that maximize monopolies and corporate profit.
12. **Reproductive and sexual health services must be comprehensive.** People should have access to the full range of reproductive health and sexual services, including comprehensive and culturally competent sexuality education and information, contraception, prenatal care, assistive reproductive technologies, abortion, and treatment and counseling for sexually transmitted infections. These services must be available without restrictions or barriers, regardless of where people live, work, or the type of insurance they have, and no one should be denied the care or information they need because of someone else's religious and/or personal beliefs. Any reforms must expand and protect access to reproductive health and sexual services, particularly for those who face the most barriers to care, including young people, people of color, immigrants, people who live in medically underserved areas, people struggling to make ends meet, and LGTBQ individuals. Preventive services including contraceptive methods and counseling must be covered with no cost sharing. Abortion services must also be fully covered and restrictions on abortion coverage must be eliminated. Further, provisions must prohibit discrimination of any kind, including participation in reimbursement programs, against health care professionals based on their participation in or support for abortion or sterilization procedures.

ENFORCEMENT

13. **Individuals must be able to enforce their rights to access care.** In any health care system, services must be physically and programmatically accessible and people must be able to enforce their rights to access health care services through administrative and judicial action and without discrimination. This includes: minimizing administrative complexity for individuals and families receiving health care services; having mechanisms to ensure sufficient provider capacity, particularly for community-based services for people with disabilities, chronic conditions, and complex medical and behavioral health needs; holding health care providers and payers accountable for making and maintaining settings that are physically and programmatically accessible; including accessible and direct processes for individuals to address issues with their care and services and appeal adverse coverage determinations; creating consumer advisory councils and other mechanisms to provide feedback and address systemic issues; avoiding placing a heavy complaint burden on individuals who may be experiencing health crises or are otherwise disincentivized from bringing enforcement actions against needed care providers; and providing access to the courts so that individuals can ensure that these protections are enforced. Individuals should receive comprehensive, medically accurate, and

scientifically valid information about their options in a language they can understand with time and structural supports to make the best decisions for themselves about their own health care.

14. **Strong protections must be included and enforceable.** For a health system to function properly, individuals must be able to advocate for themselves and their health needs. People must understand their rights and should always be provided notice of adverse decisions and have access to an appeals process when their applications for coverage or services are denied or not acted upon in a timely manner. Due process protections in Medicaid should be the minimum standard for any health insurance program.
15. **Transparency is critical to ensure informed decision making and identification of disparities.** Reforms should include transparency in relation to pricing, provider availability, cost sharing, service availability, grievance and appeals, and all other elements of health coverage. Information must be meaningful and comprehensible so that individuals can make informed decisions. Any information collected and reported, however, must ensure the privacy of patients, including but not limited to abortion services, immigration status, etc.

ENROLLMENT, OUTREACH, DATA, and QUALITY

16. **Reforms should include outreach funding and policies to encourage enrollment.** Enrollment should maximize universal take-up of health benefits. Further, sufficient funding must be provided and maintained to conduct in-language, culturally competent outreach and enrollment activities. Reforms must also include strong enrollment mechanisms that minimize gaps in coverage once implemented and ensure no costs to individuals who may move from an existing program/system into a new one. Enrollment and renewal should be available through multiple avenues (telephone, online, paper, in-person) and require no or extremely minimal paperwork documentation.
17. **Health care entities must collect and report comprehensive data.** This includes collecting and reporting data that is disaggregated, cross-tabulated, and broadly available without personally identifiable information and ensure that individuals and families have meaningful access to data about quality and affordability. The collection and reporting of quality metrics should include standards for programmatic accessibility that are embedded within quality care standards and monitoring and can be disaggregated to identify disparities based on race, ethnicity, national origin (including ethnic characteristics and immigration status), language, sex (including pregnancy and related medical conditions, termination of pregnancy, family status, sex characteristics, sex stereotypes, gender identity, and sexual orientation), class, disability, religion, age, and employment status. Resources should be provided to health care entities to help improve their data collection, analysis, and reporting capabilities. Individual privacy and confidentiality should always be protected while promoting the goal of collecting data and promoting the goal of integrated whole health. While health care entities and providers must be required to request this data, individuals must retain the choice whether to provide it.
18. **Other government health care programs must be equitable to any changes made.** Program improvements made to one health care system should be applied to all health care systems (e.g. VA, IHS, and TRICARE) to avoid exclusion of affected populations from those benefits.

19. **Clinical practice guidelines and standards of care are important tools to promote high quality care and should be followed, but their limitations must be understood and remedied.** In general, these standards and guidelines were developed based on incomplete evidence because it was generated primarily with homogenous, primarily white male subjects. Providers must be required to, at a minimum, follow standards of care where they exist, but should ensure that these standards are not used to limit access to particular treatments that may be needed, especially in populations that have been underrepresented in medical and health systems research. Further, as standards of care and clinical practice guidelines are developed or revised, developers must ensure, to the extent possible, that they are employing underlying research that is inclusive and includes data on heterogeneity of effects in different populations, including based on race, ethnicity, language, disability status, sex, sexual orientation, or gender identity. If there are heterogeneous effects, they must be incorporated in the standard or guideline. If disaggregated data is not available, or there was a lack of diversity in the underlying research, the guideline or standard must explicitly state that limitation.
20. **Ensure diversity in clinical research.** Medical research must account for the diversity of our country as new drugs, devices, and other technologies are developed. Too often, the design of clinical trials and research fail to include adequate representation of people of color, women, low income people, LGBTQ individuals, and people with disabilities, leading to beliefs and treatments that evidence shows can be limited and flawed for some populations. Historic injustices in medical research perpetrated against communities of color, particularly the African American, Native American, and Puerto Rican communities, have helped create a culture of mistrust in participating in clinical trials, and proactive efforts must be taken to address this. Health disparities may grow if the types of data underlying medical innovations and public health programs does not diversify: lack of gender and racial diversity in data can create biases in the algorithms used to power artificial intelligence, and the overwhelming preponderance of genomic data from those of European descent will have negative implications for the use and accuracy of precision medicine in the future. Further, the potential for different reactions to medications or technologies on the basis of sex points to the need to ensure gender equity in participation. The medical and scientific research communities must do more to build diverse representation in clinical trials and trust in the process. In addressing these gaps, agencies and researchers should partner with impacted communities to help guide all steps of relevant research initiatives and work to actively and appropriately recruit people of color, women, LGBTQ individuals, low income individuals, and people with disabilities.

WORKFORCE

21. **The health care workforce must be diverse and stable.** We must have a diverse, multi-lingual, multi-cultural health care workforce that reflects the makeup of our country and utilizes and fairly compensates health care workers and staff essential to the safe delivery of services, including frontline, mid-level, and community-based health care workers. All members of the health care workforce should receive a living wage, a voice on the job and in the care system, fair scheduling, paid sick time, and paid leave.
22. **Education and training programs for health professionals must be accessible and affordable for all.** Reform must provide quality education and pipeline training programs so

that individuals seeking to enter the health professions are prepared for success and that we break down barriers in access to training and post-secondary education caused by historic and present-day race-based exclusionary policies and practices. Reform must incentivize the creation of a larger and more diverse network of health care providers. Policies should encourage broader diversity of race, ethnicity, gender, sexual orientation, and provider type to expand access to comprehensive health care, increase culturally competent care, reduce health disparities, and ensure that providers reflect the populations they serve. We must also provide the frontline workforce, who often interact with patients the most, with the necessary training and tools so that they are able to help strengthen our health care system by keeping patients safe and healthy. Additionally, reforms must make college, graduate, and training programs affordable for students who are low-income and ensure that federal student aid takes into account the totality of a family's economic circumstances and full program cost, which may include childcare, transportation, and housing. Reforms should prioritize investments in grant aid first to reduce the disparate student loan debt burden placed on students who are low-income, first-generation students, women, LGBTQ individuals, and students of color.

23. **Training for health professionals must include issues related to bias, discrimination, and cultural competency.** Training and continuing education for health professionals must include identifying and addressing issues, including implicit bias, cultural competency, working with interpreters, and accessibility services.
24. **Compensation for health care providers and professionals must be equitable.** This includes equity on the basis of gender, race, and geography (among other factors), such that patients do not struggle to find high quality care that meets their needs. Primary care and obstetricians/gynecologists must also be paid sufficiently to ensure adequate access. Payment should be tied to incentives and metrics that induce providers to work towards health equity but should not penalize providers that serve the populations most impacted by health disparities. Furthermore, we recognize the value and contributions of all members of the health care workforce, including non-medical and frontline workers, including by paying them a fair and living wage.
25. **Provider networks must be comprehensive.** Protections should be in place that prevent the state and federal government from excluding providers based on anything other than their ability to provide care and operate within their legally permitted scope of practice. Patients should be able to access the providers that best fits their needs, even when they may not be geographically closest. Policies should promote the use of technology, such as telehealth and telemedicine, to increase access, including for people living in rural and remote locations. Payment and reimbursement rate for providers (and the ability of providers to negotiate that reimbursement rate) should ensure that providers will serve all patients. Reform should also ensure that provider networks are also culturally competent and language accessible since a growing, diverse population would gain access to health coverage, many for the first time.

FUNDING

26. **The system must be well-financed.** Proposals to reform the health system must provide sufficient funding to address all the issues included in these principles. The health care system

must be adequately financed to last for future generations. Funding formulas should be adopted to address counter-cyclical issues to ensure funding does not decrease during economic downturns. Funding should be non-discretionary, and block grants, caps, limits, or funding dials that make funding vulnerable to political or economic pressures must be avoided.

27. **Adequate resources and funding must be available to address health equity.** Any proposal must ensure robust and continuing resources for entities working to end health disparities and achieve health equity. This should include dedicated funding for community-based organizations, researchers, federal agencies, and state and local governments. Further, proposals must build on successful existing programs and research while promoting new efforts to ensure resources are not a barrier for organizations working to improve the health of populations impacted by health disparities.