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VIA ELECTRONIC MAIL – HHSPlan@hhs.gov

Attn: Strategic Plan Comments

Thank you for the opportunity to comment on HHS' draft strategic plan. The National Health Law Program (NHeLP) protects and advances the health rights of low income and underserved individuals. The oldest non-profit of its kind, NHeLP advocates, educates and litigates at the federal and state level.

We have organized our comments by thematic area and then provided specific edits on objectives and strategies. The main areas we address are the Strategic Plan's implications for reproductive health, people with disabilities, health equity, LGBT individuals, and people with substance use disorders. We also provide additional general comments.

I. Development of Strategic Plan

The Government Performance and Results Act (GPRA) Modernization Act of 2010 (P.L. 111-352) requires agencies to develop a Strategic Plan that provides the framework for "an

objective, quantifiable, and measurable” Performance Plan.¹ The strategic objectives in the Strategic Plan must be translatable to “clearly defined milestones” for the Performance Plan.² Unfortunately, much of HHS’ plan fails to contain strategic objectives that are amenable to performance indicators and instead moves to include political objectives – such as focusing on life beginning at conception rather than birth – rather than focus on measuring or assessing progress.

Furthermore, HHS has omitted “a description of how the goals and objectives incorporate views and suggestions obtained through congressional consultations.”³ When developing a strategic plan, HHS “shall consult periodically with the Congress, including majority and minority views from the appropriate authorizing, appropriations, and oversight committees, and shall solicit and consider the views and suggestions of those entities potentially affected by or interested in such a plan.”⁴ Congress also has the ability “to establish, amend, suspend, or annul a goal of the Federal Government or an agency.”⁵ The current strategic plan cannot be considered compliant unless and until HHS consults with the appropriate members of Congress and a public comment period is insufficient to meet these requirements.

II. Implications for Reproductive Health

i. Addressing the Health Needs of All Populations

We support Department of Health and Human Services (HHS) program and initiatives that serve and protect all individuals across the lifespan. Public health programs and policies must be based on research, evidence, and medical and health-related facts, and must be responsive to individual patient and consumer needs and wishes. However, we note that religion and conscience are not limited to those who support the idea of life beginning at conception. In fact, the vast majority of patients have religious and conscience needs and wishes that are not served using that limited framework. In order to fulfill the person-centered strategy laid out by HHS, consumers require medically accurate, evidence-based, unbiased comprehensive health care services so that they can use their own decision making capacity to choose health care services that comport with their individual morality and circumstances. This means that reproductive health care services, including hormonal contraception, sterilization, and pregnancy termination, must be available to all who desire those services in accordance with their own individual beliefs.

We are concerned that HHS is inserting concepts such as “the unborn” and life “from conception” into its strategic plan. These concepts run contrary to medical and health-related evidence and standards of care, and instead reflect one particular religious point of

¹ 31 U.S.C. § 1115(b)(2), § 1115(c).

² 31 U.S.C. § 1115(b)(5)(B).

³ 5 U.S.C. § 306(a)(5).

⁴ 5 U.S.C. § 306(d).

⁵ Pub. L. 111–352, §15, Jan. 4, 2011, 124 Stat. 3883.

view that has no role in advancing and protecting the public health of a diverse population. Elevating a fertilized egg to equal status with a person is contrary to U.S. law and establishes a policy framework that would undermine the ability of women and others to make the best decisions for themselves and their families, including decisions impacting their health and well being, and their ability to participate in public life.⁶ Such policies will impede the ability of HHS to cultivate and inform best practices for women’s health, and in turn, interfere with the ability of providers, particularly those who offer reproductive health services, to provide quality care to their patients.

Second, one of the basic functions of government is to ensure the health and well-being of its population. Privileging embryos and fetuses over people threatens the capability of HHS to fulfill this function, and would deprive women of health care benefits that medical and health care experts recognize as critical to ensuring women’s health and well being.⁷ Elevating the status of a fetus over the health needs of pregnant women would result in poorer maternal health and poorer birth outcomes.⁸ Moreover, adopting policies that give health rights to fetuses would also undermine a woman’s constitutional right to access abortion, and interferes with the patient-provider relationship by limiting the information, counseling, referral and provision of abortion services that a woman can receive, despite the fact that these are part of the standard of care for a range of common medical conditions including heart disease, diabetes, epilepsy, lupus, obesity, and cancer. The language is overly broad, confusing, and subject to misuse and abuse by creating a federal health care framework that invites HHS to refuse to participate in the orderly delivery of evidence-based health care services.

Third, the language is contrary to both the Establishment Clause and the Free Exercise Clause of the U.S. Constitution. The idea that “life begins at conception” is not an evidence-based theory, but a religious one, which the vast majority of individuals that HHS serves do not share. Free speech and religious liberty are concepts that cannot be limited to one specific view; those who do not believe that life begins at conception are entitled to the same free exercise of religion, and any language to the contrary is decidedly discriminatory. The decision to obtain any health service, including reproductive health care, should remain with the individual.

We thus suggest modifying the language in the following sections:

⁶ Roe v. Wade, 410 U.S. 113, 153 (1973); Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 856 (1992).

⁷ AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, COMMITTEE OPINION: INCREASING ACCESS TO ABORTION (2014), <https://www.acog.org/-/media/Committee-Opinions/Committee-on-Health-Care-for-Underserved-Women/co613.pdf?dmc=1&ts=20171019T1538434634>.

⁸ CENTER FOR REPRODUCTIVE RIGHTS AND IBIS REPRODUCTIVE HEALTH, EVALUATING PRIORITIES: MEASURING WOMEN’S AND CHILDREN’S HEALTH AND WELL-BEING AGAINST ABORTION RESTRICTIONS IN THE STATES (2017), <https://ibisreproductivehealth.org/sites/default/files/files/publications/Evaluating%20Priorities%20August%202017.pdf>.

Line 60:

HHS accomplishes its mission through programs and initiatives that cover a wide spectrum of activities, serving and protecting Americans at every stage of life, ~~beginning at conception.~~

Line 114:

[O]ur ultimate goal is to improve healthcare outcomes for all people, ~~including the unborn,~~ across healthcare settings.

Line 846:

A core component of the HHS mission is our dedication to serve all Americans ~~from conception to natural death[.]~~

Line 1142:

~~The research pursued under this strategic goal is to be conducted consistent with the understanding that human subjects protection applies to all human beings from conception to natural death.~~

Line 1342:

[T]o augment scientific opportunities and innovation for public health needs, consistent with human subject protections, ~~which protect all persons from conception on,~~ and bioethics

B. Preventive Care

We greatly appreciate HHS' recognition of the importance of consumer-driven preventive care, as illustrated on lines 130, 142, 144, 187, 251, 536. Contraception and family planning are some of the most well-researched and proven effective methods of preventive care.⁹ They are particularly important in achieving Healthy People 2020's goal to "improve

⁹ INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES, CLINICAL PREVENTIVE SERVICES FOR WOMEN: CLOSING THE GAPS (2011), http://nationalacademies.org/hmd/~media/files/report%20files/2011/clinical-preventive-services-for-women-closing-the-gaps/preventiveservicesforwomenreportbrief_updated2.pdf.

pregnancy planning and spacing, and prevent unintended pregnancy.”¹⁰ Access to contraception and preventive care is vital to ending health disparities that women of color face, including unintended pregnancy and high rates of cervical cancer incidence and mortality. The medical and health-related standard of care for some women with chronic medical conditions or taking certain medications is to use contraception to prevent pregnancy until their conditions are under control to improve maternal health and birth outcomes. For example, women taking accutane for severe acne are advised to use two forms of contraception.¹¹ Barriers to post-partum contraception are strongly associated with poor health outcomes including very low birth weight, infant mortality, and maternal mortality when women cannot ensure safe intervals between pregnancies.¹² Moreover, we believe that recent administrative actions, including those that undermine the marketplaces, stopped payment of cost-sharing reductions of the Affordable Care Act, and the released interim final rules regarding the contraceptive coverage benefit, are inconsistent with promoting preventive care and strengthening the economic and social well-being of individuals across the lifespan.

We recommend amending the below language as follows:

Line 149 (Objective 1.1):

- Reduce need for avoidable medical **and health care** costs by increasing use of timely **contraceptive**, prenatal, maternal, and postpartum care

C. Disease Outbreaks and Public Health Emergencies

We strongly support HHS’ strategy to enhance the connections between public health and health care for early detection and efficient responses to disease outbreaks and public health emergencies. We note that family planning clinics play a critical role in early detection of disease outbreaks and public health emergencies, such as the Zika virus. As noted above, any partnership with faith-based organizations must require comprehensive sexual education, screening, and planning, and must prohibit discrimination. To do otherwise will only undermine the goals of early detection and efficient response. As was seen in the outbreak of the Zika virus, public health emergencies can disproportionately harm women of reproductive age. We thus suggest HHS includes in its strategies the impact of these disease outbreaks and public health emergencies on reproductive health,

¹⁰ OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION, HEALTHY PEOPLE 2020 TOPICS & OBJECTIVES: FAMILY PLANNING, <https://www.healthypeople.gov/2020/topics-objectives/topic/family-planning>.

¹¹ U.S. FOOD AND DRUG ADMINISTRATION, INFORMATION FOR HEALTHCARE PROFESSIONALS: ISOTRETINOIN (MARKETED AS ACCUTANE) (2005), <https://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/DrugSafetyInformationforHealthcareProfessionals/ucm085227.htm>.

¹² Agustín Conde-Agudelo et al, *Effects of Birth Spacing on Maternal, Perinatal, Infant, and Child Health: A Systematic Review of Causal Mechanisms*, 43 STUD. FAM. PLAN. 93 (2012), available at https://www.k4health.org/sites/default/files/conde-agudelo_2012.pdf.

and that family planning clinics are included in any emergency response to the fullest extent when implementing the following objectives.

We recommend the following changes:

Line 224 (Objective 1.2)

- Enhance the connections between public health and health care for early detection and efficient response to healthcare-associated disease outbreaks, **including those that impact reproductive health**

Line 829 (Objective 2.4)

- Enhance international preparedness through **evidence-based** medical countermeasures and community mitigation measures, respecting the inherent dignity of persons ~~from conception to natural death~~, **including people of reproductive age**

D. Consumer Choice and Empowerment in Relation to Faith-Based Organizations

We agree with HHS' affirmation of the importance of consumer choice and empowerment, but note that consumer choice and empowerment must be driven by fully informed, patient-centered decision making. Throughout the HHS Strategic Plan, the department refers to "evidence-based" recommendations (e.g. lines 237, 353, 937 to name a few). Faith-based organizations that participate in health care delivery, research, or other HHS activities must be held accountable to engage in medically accurate, evidence-based, non-discriminatory, and unbiased activities. Many faith-based organizations adhere to these principles, however, some faith-based organizations impose one perspective of religious beliefs on the public. When hospitals, clinics, and individual health care providers have the ability to refuse patient care based on religious or moral beliefs, patients may suffer devastating health consequences.¹³ The harms caused by refusals to provide care have a disproportionate impact on those who already face multiple barriers to care, including communities of color, LGBTQ individuals, people facing language barriers, and low-income families and individuals. Requirements that all organizations including those that are faith-based provide unbiased, non-discriminatory, evidence-based information and services is

¹³ For documented examples of religious healthcare providers denying care to patients on the basis of religious beliefs, see Compl. 2, *ACLU of Mich. v. Trinity Health Corp.*, 2016 U.S. Dist. LEXIS 30690 (E.D. Mich. Mar. 10, 2016); Freedman et al., *When There's a Heartbeat: Miscarriage Management in Catholic-Owned Hospitals*, 98 AM. J. PUBLIC HEALTH 1774 (2008), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2636458/>; National Women's Law Center, *Refusals to Provide Health Care Threaten the Health and Lives of Patients Nationwide*, <https://nwlc.org/resources/refusals-to-provide-health-care-threaten-the-health-and-lives-of-patients-nationwide/> (last visited Oct. 20, 2017).

not a “barrier” to be removed, but is a consumer and patient protection to be upheld. Any deviation from these standards should not be allowed.

Patients cannot make fully informed decisions when access to pertinent health information is deliberately withheld. We oppose all efforts to limit the provision of health information, including but not limited to when it concerns the full range of contraceptive options including sterilization, abortion, and LGBTQ-inclusive sexual health information. Additionally, adolescents have a unique need for access to confidential sexual health information, as fears about disclosure may discourage them from seeking preventive care. Any efforts by faith-based organizations or providers to limit the information and access that patients are entitled to receive, even when the organization may not provide those services itself, is incompatible with true consumer choice and empowerment and would serve to completely undermine attempts to support healthy decision making. We thus recommend including the full scope of sexual and reproductive health services information when implementing the following objectives and recommend the following changes:

Line 314 (Objective 1.3)

Improving access to health care involves multiple strategies – from improving healthcare coverage options, to improving consumer understanding of options, to designing options responsive to consumer demands, ~~while removing barriers for faith-based and other providers,~~ **and ensuring that faith-based organizations adhere to requirements to provide evidence-based, unbiased, and non-discriminatory information and services**

Line 332

- Support consumer choice and transparency by promoting the availability of a range of individual health insurance plans, and other health care payment options, including faith-based options **that cover all required services and do not discriminate**, with different benefit and cost-sharing structures

Line 353 -- delete the following language

Design healthcare options that are responsive to consumer demands, ~~while removing barriers for faith-based and other community-based providers~~

Line 489 (Objective 2.1)

- Communicate culturally competent, ~~and linguistically appropriate,~~ **unbiased, and non-discriminatory** messages, delivered by appropriate messengers, including ~~faith-based and other~~ community organizations, in plain language and in alternate formats for persons with disabilities, using approaches that leverage new and emerging communications technologies

Line 502

- Provide adolescents with information, **including comprehensive sexual and reproductive health information**, and support to make healthy decisions regarding their health and well-being

Line 1357 (Objective 4.3)

- Fund research on shared decision making to support healthcare providers' efforts to deliver healthcare services that empower patients, families, and caregivers to implement **personally chosen** lifestyle behavior modification aimed at better health and healthcare outcomes

Line 1440 (Objective 4.4)

- Disseminate patient-centered outcome research findings, **including evidence-based findings on reproductive and sexual health**, to health professionals and organizations that deliver health care

E. Provider Shortages

Family planning clinics are critical Medicaid providers, and HHS should take full advantage of all willing and able providers. We thus suggest including family planning providers to the fullest extent when implementing the following objective:

Line 384 (Objective 1.3)

- Simplify enrollment, eliminate barriers to retention, and address shortages of healthcare providers who accept Medicare or Medicaid, **including comprehensive family planning clinics**, and providers who offer specialized care

F. Protections for Religious Providers

We appreciate HHS' desire to strengthen and expand the healthcare workforce. However, federal law provides ample protections and religious exemptions, such as the Church Amendments, for health care entities and individuals who object to providing certain services based on their religious beliefs. The Strategic Plan cites no evidence that further protections are needed, and we note that additional provisions to shield these providers from delivering evidence-based, quality medical and health-related services that meet the standard of care would be unnecessary and restrictive. These religious exemptions harm women and LGBTQ individuals. Denials of care undermine the Affordable Care Act's intention to ensure all women receive comprehensive contraceptive coverage of the full

range of FDA-approved drugs and devices, with the individual deciding the appropriate choice of method. They also interfere with the patient-provider relationship by limiting the information, counseling, referral and provisions of contraceptive and abortion services that woman can receive, despite the fact that these are part of the standard of care for a range of common medical conditions including heart disease, diabetes, epilepsy, lupus, obesity, and cancer. Denials of care may exacerbate health disparities and put individuals in life-threatening circumstances. For this reason, we strongly oppose the inclusion of Executive Order 13798 of May 4, 2017, Promoting Free Speech and Religious Liberty in lines 359 through 371. We believe the enforcement and implementation of this executive order will further undermine the ability of women and LGBTQ individuals to receive comprehensive health care, including reproductive health care. Additionally, this language fails to acknowledge that many health care providers have moral convictions telling them that that they must provide services that patients need, including abortions. HHS is responsible for enforcing federal law that protects individual health care providers from employment discrimination due to their providing abortions and other care. We thus suggest modifying the below language as follows:

Objective 1.3

We recommend deleting the following beginning on line 359:

~~Vigorously enforce laws, regulations, and other authorities, especially Executive Order 13798 of May 4, 2017, Promoting Free Speech and Religious Liberty, to reduce burdens on the exercise of religious and moral convictions, promote equal and nondiscriminatory participation by faith-based organizations in HHS-funded or conducted activities, and remove barriers to the full and active engagement of faith-based organizations in the work of HHS through targeted outreach, education, and capacity building.~~

~~Implement Executive Order 13798 of May 4, 2017, Promoting Free Speech and Religious Liberty, and identify and remove barriers to, or burdens imposed on, the exercise of religious beliefs and/or moral convictions by persons or organizations partnering with, or served by HHS, and affirmatively accommodate such beliefs and convictions, to ensure full and active engagement of persons of faith or moral conviction and of faith-based organizations in the work of HHS.~~

Delete the following beginning on line 371:

~~Promote equal and nondiscriminatory participation by persons of faith or moral conviction and by faith-based organizations in HHS-funded, HHS-regulated, and/or HHS-conducted activities, including through targeted outreach, education, and capacity building.~~

Line 399 (Objective 1.4)

HHS is investing in a number of strategies to strengthen and expand the healthcare workforce -- from reducing provider shortages, to providing professional development opportunities for the healthcare challenges of today and tomorrow, to ~~removing barriers for~~ **ensuring** health care providers with religious beliefs or moral convictions **adhere to the medical and health-related standard of care and do not discriminate**, to collecting and analyzing data for continuous improvements.

G. Telehealth

We agree that telehealth models are a critical tool in addressing health equity. We believe that telehealth models are well suited to provide a spectrum of services including sexual and reproductive health services, particularly for those living in rural and underserved areas, including contraceptive counseling, medication abortion provision, and prenatal and postpartum counseling. We thus suggest including sexual and reproductive health services when developing models under the following objective:

Line 420 (Objective 1.4)

- Support development of telehealth models to increase access to care, **including reproductive health care**, in rural and underserved areas

H. Supporting Women's Health and Healthy Pregnancies

We strongly support expanding access to supports for healthier living, including for women. Women's health services must encompass age appropriate services across the lifespan, including all preventive services identified by the Institute of Medicine and the U.S. Preventive Services Task Force, and services that allow women to determine if, when, and how to plan their families, in line with HHS' objectives of promoting empowered patient decisionmaking.

We appreciate HHS' attentiveness to a wide spectrum of women's health needs, including pregnancy. We support efforts to enable and empower parents to reduce childhood obesity, alcohol use disorder, and opioid use, and believe HHS should support, encourage, and expand voluntary programs that educate parents about the health consequences of obesity and substance use for themselves and their children throughout the lifespan. In addition, HHS should support more extensive availability of healthy foods including in underserved neighborhoods and in schools, and voluntary substance use disorder programs.

We thus recommend modifying the below language as follows:

Line 538 (Objective 2.1)

- Increase access to preventive services, to breastfeeding supports, to adaptive mammography equipment in clinics, to women’s health services that improve the incidence of healthy ~~childbirth~~ ***health outcomes throughout life span development***, including ***but not limited to preconception/prenatal/pregnancy care and supports, and encourage and support lactation accommodations***

Line 630 (Objective 2.2)

- Accelerate research and national efforts to implement solutions at the individual, family and community level, including through partnerships with faith-based and community organizations, to ***support parents and potential parents in reducing*** childhood obesity, including focusing on the pregnancy period to age five in terms of the etiology and interventions

Line 669 (Objective 2.3)

- Increase healthcare providers’ use of alcohol use disorder screening and brief intervention approaches to ***support and empower individuals to*** reduce consequences of ~~risky behavior~~ ***alcohol use disorder throughout all stages of lifespan development***, including effects of alcohol use in pregnancy.

Line 975 (Objective 3.3)

- ***Promote programs and services that enable*** ~~women and their unborn children~~ ***individuals to avoid*** ~~from harm and harmful exposures during pregnancy~~ ***all stages of lifespan development***, and promote recommended protective prenatal and postpartum behaviors, including encouragement of breast-feeding when possible

Line 1210 (Objective 4.1)

- Strengthen understanding of the opioid crisis through better public health surveillance to inform clinical management decisions ~~for~~ ***made in consultation with*** patients, including effects of opioid use ~~in pregnancy~~ ***on fetal development*** and neonatal abstinence syndrome

I. Adolescent Health

We strongly support expanding resources, supports, and information for adolescents so that they can make the best decisions for their health and well-being. However, programs and information supported under this strategic plan must include age, developmentally and culturally appropriate, medically accurate, evidence-based sexual and reproductive health information to ensure that adolescents have the tools they need to make informed and

healthy decisions throughout their lives. The inclusion of faith-based organizations that engage in discriminatory or disparaging behavior in programming and education relating to adolescents undermines the ability of young persons to gain comprehensive, LGBTQ-inclusive, unbiased sexual and reproductive health information and may stigmatize LGBTQ youth and their relationships. Faith-based organizations must be required to guarantee the confidentiality of services and counseling that adolescents need when accessing health services, particularly reproductive health services. Any information and programming regarding human sexuality and healthy relationships must not discriminate or stigmatize the LGBTQ community. We thus recommend modifying the below language as follows:

Line 507 (Objective 2.1)

- Partner with private organizations, including faith-based and community organizations, to develop and implement programs that enable people to make ***individually elected*** healthy life choices

J. Suicide Prevention

We appreciate HHS' interest in promoting evidence-based suicide interventions. We note that LGBTQ youth have the highest rates of youth suicide, and support HHS in fulfilling its legal responsibility to ensure non-discriminatory and fully inclusive health services for these populations. That is, we support comprehensive sexual and reproductive health counseling and services from LGBTQ-competent providers, and discourage use of faith-based partners that shame LGBTQ individuals and communities based on specific ideological beliefs. We thus suggest modifying the below language as follows:

Line 725 (Objective 2.3)

- Prevent suicides and suicide attempts by expanding evidence-based approaches for adults and youth, ***and addressing the root cause(s) of suicidal depression in these populations***

K. Healthy Relationships and Interpersonal Violence

We strongly support HHS' dedication to promoting healthy relationships, including but not limited to marital relationships, and believe that curbing interpersonal violence is an important component of HHS' service. We note the inherent link between women's reproductive health and exposure to violence. Intimate partner violence can directly impact women's reproductive and sexual health, increasing risk for unintended pregnancies and abortions, miscarriage, and sexually transmitted infections. To the extent that some faith-based organizations promote the institution of marriage over individual rights and well-being, we believe they will undermine HHS' strategies. We thus recommend considering the importance of reproductive and sexual health in relation to preventing interpersonal violence and promoting healthy relationships when implementing the following objectives:

Line 940 (Objective 3.2)

- Invest in rigorous research and evaluation of domestic violence programs, including those provided by faith-based and community organizations, increase support for community based services for victims **and survivors** of domestic and dating violence, and provide training and technical assistance to build their capacity to serve victims **and survivors** of intimate partner abuse, especially those from underserved communities

Line 947

- Expand interagency partnerships and systems to train health care and human service providers to assess for domestic violence and do brief interventions to link victims **and survivors** to safety and support services, including through faith-based and community organizations

Line 963 (Objective 3.3)

- Support strong families and healthy ~~marriage~~ **relationships**, and prepare children and youth for healthy, productive lives

Line 1020

- Support faith-based and community organizations to promote strong, healthy family formation and maintenance through programs that combine ~~marriage and~~ relationship education services with efforts to address participation barriers, economic stability, and needs of their participants

L. Government-Sponsored Research

We support HHS' goals of enhancing ethical and evidence-based health research. In the context of HHS's research portfolio into leading causes of death, we recommend that HHS add a research focus on the disproportionate incidences of maternal death and morbidity, as well as low-birth-weight and preterm births to African-American women. These pernicious disparities should be investigated, and strategies developed to address them. We recommend adding a new topic for research and funding:

Add new bullet to Objective 4.3

- **Support and fund research to identify and address the causes of high rates of maternal mortality, maternal morbidity, and poor birth outcomes for African American women.**

III. Implications for People with Disabilities

HHS's strategic plan appropriately addresses issues related to individuals with disabilities throughout the entire plan, recognizing that accessibility, community-integration and self-determination are implicated in almost every aspect of health care. Our comments below seek to clarify and strengthen HHS' strategies to promote the following four goals: expansion of access to services in the context of behavioral and physical health collaborative models; promotion of community-integration and inclusion; protection of the right to person-centered services and self-determination; and protection all other individual rights.

A. *Physical and Behavioral Health Integration*

We appreciate HHS' commitment to promoting collaborative models of behavioral and physical health care. Such collaboration has the potential to both address shortages of behavioral health professionals via consultative models, and to address unmet physical health care needs of individuals receiving behavioral health care services. To the extent these models focus on the former by expanding the reach of behavioral health professionals via screening, telemedicine, and/or other consultative models, HHS should ensure that such approaches are coupled with an explicit commitment to expanding and integrating essential community-based behavioral health support services. Essential community-based services include, but are not limited to, Peer Support Services, Assertive Community Treatment, Mobile Crisis Intervention, and various other intensive community-based services.

Consultative models allow primary care providers to address non-intensive behavioral health needs in an office-based setting, increasing the ability of primary care providers to screen and identify behavioral health issues. However, screening and identification is of limited use to individuals with significant needs (whose needs cannot be met in a traditional office setting) if high quality, person-centered, community based services are not readily accessible post-screening. We appreciate that in some sections, HHS is clear about connecting screening of individuals with ensuring access to high-quality, responsive services, (see e.g. Objective 2.3, where the sub-strategy to expand prevention and screening is linked to the next sub-strategy of improving access to high-quality care and treatment), but believe that this connection should be explicit in all sections of the plan.

We recommend the following changes in light of these comments:

Line 273-274

- Implement a collaborative model, ***integrating*** behavioral health, primary care, and ***community-based support services***, that is team-driven, population-focused, ***person-centered***, measurement-guided, and evidence-based.

Line 335-336

- Improve access of dual Medicare-Medicaid beneficiaries to fully integrated physical **health care**, and behavioral **health care**, **and community-based supports and services options**.

Line 658-659

- Educate and empower individuals and communities, including through partnerships with faith-based and community organizations, to recognize the signs of serious mental illness and substance use disorders, to encourage screening and identification of such problems, **and to ensure that individuals who are screened and/or identified are promptly referred to available, accessible, and community-based services and supports to address identified needs**.

B. Promoting Person Centered Services and Self-Determination for Individuals with Disabilities

The strategic plan contains numerous strategies to improve communication and health care decision making. We support these strategies. We offer the following suggestions to ensure that patient-provider communication tools reflect commitment to models that integrate informed consent principles and make individuals full partners in improving their own health.

Under Objective 1.2, in the section entitled “Empower patients, families, and other caregivers to facilitate the deliver and increase the use of safe, high-quality, person-centered care,” we suggest HHS provide further explanation regarding how this strategy can be implemented. We suggest adding the following bullet point after line 276:

- **Promote the development and implementation of tools that expand person-centered decision-making regarding health care services**

In addition, we suggest revisions to the following strategies to prioritize the values of self-determination and informed consent:

Lines 284-286

- Enhance the use of health information technology among safety net providers and community-based organizations to inform decision-making **based on the principles of informed consent and shared decision-making**, better engage patients in their care, improve public health outcomes, and increase public health reporting.

Lines 423-425

- Increase awareness and promote use of clinical decision-support and patient-provider communication **and shared decision-making** tools; share evidence-based practices and training opportunities to provide safety and scientific knowledge to the workforce.

Lines 493-495

- Support programs and build partnerships with organizations that build the health literacy skills of disadvantaged and at-risk populations, and promote proven methods of checking understanding to ensure individuals understand health and prevention information, recommendations, and risk and benefit tradeoffs, **and have the tools necessary to practice informed consent**

Last, we appreciate HHS' acknowledgment that some of the barriers to treatment pursuant to HIPAA may be "perceived barriers." As HHS investigates such barriers, we encourage HHS to promote solutions that protect individual privacy while promoting self-direction and advanced planning. Advance directives for behavioral health care (also known as psychiatric advanced directives) are one such legal tool which allow individuals to designate types of treatment and settings in which they want to receive care, and allow them to designate certain individuals or providers that should be notified regarding treatment needs. The following edits will promote the use of such tools:

Line 542-544:

- Support patient, consumer, and caregiver involvement in care planning, **including but not limited to the use of advance health care directives and advance directives for behavioral health care**, to ensure that care is person-centered, **and responds** ~~responding to~~ **all** the needs and wishes of those being services., ~~including their religious or conscience needs and wishes.~~

Lines 736-739:

- Address the barriers, real or perceived, under Health Insurance Portability and Accountability Act (HIPAA) and 42 CFR Part 2, to the sharing of mental health and substance use disorder information, through health information exchange, or otherwise, with other health care providers and with family members and friends of persons ~~suffering~~ with such illnesses **by promoting strategies, such as the use of advanced mental health directives and other voluntary information-sharing devices, to protect individuals' right to privacy while promoting access to information necessary to coordinate services and supports.**

Lines 1119-1121

- Include culturally appropriate, person- and family-centered care planning in federal social and healthcare services for older adults and persons with disabilities to protect individual choice and address a person's current and future economic resources, including advanced care planning needs. **Promote the use of supported decision-making and other alternatives to guardianship that maximize individual autonomy and choice.**

C. Community Integration and School Inclusion

We appreciate that HHS has included a section regarding improving Home and Community-Based Services (HCBS), and that HHS makes explicit mention of the well-established and crucial right to community integration and inclusion in numerous sections of the strategic plan. While we encourage the development of additional community supports to enhance community integration, we caution against relying on such supports in place of paid supports. Paid supports are critically different from natural and community supports, and one cannot simply be substituted for the other. Furthermore, NHeLP supports the goal of improving the quality of HCBS services and community-based mental health services by developing a core set of measures and promoting evidence-based and promising practices. Below are several suggestions to strengthen this language:

Line 394-395

- Remove barriers to **community-integration**, inclusion, and accessibility for people with disabilities in public health programs (e.g., communication, physical environment, workforce competencies for public health and healthcare professionals) **by rigorously enforcing the nondiscrimination provisions included in the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act.**

Lines 661-662

- Ensure early screening of children and youth to identify those with or at risk for serious emotional disturbance and substance use disorders, ~~and~~ expand access to integrated, **home, community, and school-based** mental health and substance use disorder services.

Lines 664-665

- Promote healthy development, including social and emotional development in young children, **and community-wide initiatives to reduce exposure to**

trauma and adverse childhood experiences, to avoid behavioral problems and promote school readiness, learning, and **long-term behavioral health**.

Lines 692-693

- Support broad adoption of evidence-based supported housing, supported employment, **mobile crisis services, assertive community treatment** and supported education programs, **and specialty children's services such as intensive home based services, intensive care coordination and therapeutic foster care.**

Lines 708-709

- Promote the health and independence of older adults with or at risk for behavioral health conditions (i.e., mental illness, substance use disorders, suicide) through improved collaboration with federal and non-federal stakeholders **and through increasing access to and availability of home and community-based long term supports and services that provide full support to allow individuals to live and fully participate integrated settings.**

Lines 984-986

- Promote healthy development in young children to avoid behavioral problems and **community-wide initiatives to reduce exposure to trauma and adverse childhood experiences** to promote school readiness, and learning, **and long-term behavioral health**, and offer parents of young children access to evidence-based, culturally-appropriate, **child and family-centered** parenting education and supports.

Line 1039

- Integrate trauma-informed, family-focused, **home and community based** behavioral health **supports and** services with pediatric primary care.

Lines 1069-1070

- Promote independence of older adults and people with disabilities through improved federal collaboration, including with faith-based and community organizations, to ensure opportunities to live and receive services in **their own homes and communities, in the most integrated setting appropriate to their needs, including integrated opportunities for active community participation in all areas of life.** community

Lines 1072-1073

- Foster culture change through inclusion and accessibility for children and adults with disabilities and older adults **by robust implementation and enforcement of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act.** ~~and removing physical and other barriers~~

Lines 1074-1076

- Ensure programs for people with disabilities and older adults help protect them from all forms of abuse, including physical, mental, emotional, and financial abuse, and help ensure their ability to exercise their rights to make choices, contribute to their communities, and live independently **in integrated settings, and in a way that facilitates the greatest opportunities for active community participation in all areas of life.**

Lines 1083-85:

- Pursue initiatives and programs to provide support to older adults, people with disabilities, and their families and caregivers **to allow individuals to remain in their homes and communities, and to provide support** as individuals move ~~between~~ **from** institutional settings, ~~and home~~ **to more integrated settings, that facilitate the greatest opportunities for active community participation in all areas of life.**

Lines 1101-1102

- Assist states in strengthening and developing high-performing long-term services and supports systems that focus on the person, provide streamlined access, and empower individuals to participate in community living **in the most integrated setting appropriate to their needs, with opportunities for active community participation.**

D. Protection of Other Rights: Protection from Abuse and Neglect, Mental Health Parity, Accessibility, Family Integrity, and Returning Citizens

Choice of providers for mental health and substance use treatment services is often quite limited. Care must be taken to ensure that all individuals are able to access care free of discrimination. The risk of discrimination is heightened in mental health or substance use treatment settings that are residential, intensive, or both, as with intensive and/or residential services, providers are more intimately involved with individuals' daily lives.

We recommend the following changes:

Lines 693-695

- Engage individuals and communities, including through faith-based and community organizations, **to provide culturally competent, accessible, and non-discriminatory** social and community recovery support.

HHS' commitment to protecting individual rights and addressing abuse and neglect should be clarified to ensure it is clearly applicable in all facilities where individuals with disabilities receive services, not just in traditional health care settings. For example, Protection and Advocacy organizations, the entities established by federal law and administered through ACL and SAMHSA to monitor, investigate, and advocate against abuse and neglect of individuals with disabilities, are permitted access to broad swath of facilities, including juvenile detention facilities, homeless shelters, and jails and prisons, for the purposes of addressing abuse, neglect and rights violations. HHS' strategies should ensure HHS' commitment to protecting the rights of individuals is employed in all appropriate settings.

Lines 696-697

- Ensure that individual rights are protected including addressing abuse and neglect **in facilities and programs that render care, supports, or services to individuals with disabilities; mental health parity, access to services and supports in the most integrated setting as required by Olmstead's integration mandate and the Americans with Disabilities Act**, and other protections **including but not limited to the right to informed consent, choice, and privacy.**

Protection from abuse and neglect must be built into emergency planning. People with disabilities and older adults too often bear the brunt of poor disaster planning, and may need additional assistance to safely survive emergencies. For example, when Hurricane Irma was approaching Florida, officials announced their intent to use mental health commitment laws to involuntarily hold homeless individuals in psychiatric hospitals until the storm passed. While all individuals should be able to seek shelter, use of force is not the solution, particularly when serving the needs of individuals with psychiatric disabilities. Instead, we hope that HHS prioritizes strategies involving incorporating the input of people with psychiatric disabilities in the long-term planning for natural disaster evacuation efforts, maximizing communication via trusted channels and institutions, and offering low-barrier shelters to assist with evacuation.

We recommend the following changes to incorporate these considerations into HHS' strategies:

Lines 762-766

- Provide expertise and tools to state and local governments, health systems and facilities, and other organizations, including faith-based and community organizations, to strengthen their capabilities to provide continuous, safe, **culturally competent, accessible, non-discriminatory** and effective health care, public health services, and/or social services during emergencies and through the recovery period, including when such care or services may need to be delivered in alternate settings or by alternate mechanisms.

Lines 786-788

- Ensure that the needs of disadvantaged and at-risk populations are met in emergencies, through effective integration of traditionally underserved populations into planning, response, and recovery efforts, **and by creating and implementing plans to ensure that the needs of individuals with limited income, limited mobility, or special health needs are met during emergencies.**

While we appreciate HHS' stated commitment to providing substance use treatment to parents to "allow families [to] remain intact," in lines 683-684, we believe that this commitment should be made explicit throughout the plan. Therefore, the following lines should read:

Lines 981-983:

- Improve services to children and families involved in the child welfare system as a result of a parental or caretaker opioid or other substance use disorder, **by supporting funding and access to treatment (including Medication Assisted Treatment) to parents or caretakers in order to promote family reunification,** including through faith based and community organizations.

Last, we object to HHS' characterization of a lack of "personal responsibility" as the barrier to employment for returning citizens, without acknowledgement of discriminatory hiring practices, disability and/or trauma and restrictive conditions of release as major reasons for unemployment. Reentry support should be a long-term investment that addresses both structural and individual barriers to work. Lines 878-883 should be edited as follows:

- Increase access to comprehensive services (i.e., health, behavioral health, student loans, public assistance, and public housing) through ~~short-term, transitional~~ public welfare services and partnerships with other federal agencies and faith-based and community organizations, help formerly incarcerated individuals ~~develop habits of personal responsibility, including obtaining and maintaining~~ **health and social service supports that assist in gaining**

meaningful employment, reconnecting with their children and families, paying child support, and avoiding recidivism.

IV. Implications for Health Equity

The current HHS Strategic Plan for FY2014-2018 establishes specific measurable goals to improve the health outcomes of all individuals by specifically recognizing the health disparities that persist among vulnerable populations, including racial and ethnic minorities, individuals with disabilities, refugees, lesbian, gay, bisexual, and transgender (LGBT) individuals.¹⁴ HHS must continue to undertake activities to identify and address health disparities with the ultimate goal of eliminating them. In activities spanning the Office for Civil Rights, Office of Minority Health, Office of Women's Health as well as the Centers for Medicare & Medicaid Services, all of HHS' endeavors must ensure that disparities are not heightened but are prevented. We appreciate recognition of the need to address disparities within the Strategic Plan but believe that HHS must strengthen these sections to ensure all individuals can achieve their health equity.

Further, the Strategic Plan should ensure that all of HHS' activities are undertaken in a culturally competent manner. Providing culturally competent services is critical to ensure that services are client/patient centered and are appropriate for not just the particular program at issue but also for the clients/enrollees served. We urge HHS to include more specific and measurable goals and strategies to address cultural competency in a holistic manner including race, ethnicity, language, immigration status, age, disability, sex, gender identity and sexual orientation.

A. Strategic Goal 1

i. Strengthen informed consumer decision-making and transparency about the cost of care, line 158

We support HHS' recognition of the need for health literacy tools. We suggest this strategy specifically recognize the need to provide culturally competent tools such that all individuals, regardless of their background, can benefit from these tools. We thus recommend the following amendment to this strategy:

Line 164

- Support *culturally competent* health literacy tools and partner efforts to promote understanding of health costs and terminology, so that consumers can choose the most appropriate, affordable health plan that meets their health needs”

¹⁴ See, e.g., HHS Strategic Plan 2014-2018, Strategic Goal 1 Objective E; HHS Action Plan to Reduce Racial and Ethnic Health Disparities (2011).

Line 167: we also recommend adding CHIP to the following bullet:

- Increase education and awareness of coverage options such as Medicaid, **CHIP**, Medicare Fee- For-Service, Medicare Advantage, Prescription Drug Plans, and integrated care options” add CHIP

ii. **Strengthen coverage options to reduce consumer costs, line 173**

We appreciate the recognition of the need to streamline eligibility and enrollment processes. We note, however, that such efforts should include CHIP as well as be provided in a culturally competent manner. We suggest the following changes to this bullet:

Line 178

- Streamline eligibility and enrollment processes for Medicare, Medicaid, **CHIP**, and other community supports so that all populations, including individuals most in need, have access to the services they need. ***Ensure these efforts are culturally competent.***

iii. **Collect, analyze, and apply data to improve access to affordable health care, Line 196**

We recommend adding a new bullet that addresses collecting, analyzing and applying **demographic** data. This would read as follows:

- ***Provide information stratified by race, ethnicity, language, sex, gender identity, sexual orientation, age and disability; race and ethnicity data should be disaggregated.***

B. Strategic Goal 1, Objective 1.2

We appreciate HHS’s mention of the need to reduce disparities. We believe this includes not merely racial and ethnic health disparities but also disparities based on language, age, sex, sexual orientation, gender identity, and disability. We recommend HHS include a broad definition of health care disparities in its strategic plan.

i. **Improve patient safety and prevent adverse events such as healthcare-associated infections and medication harms across the healthcare system, Line 220**

We appreciate HHS’ recognition of the need to improve the use of public health and health care data. We suggest that HHS also specifically mention the need to include the **collection** of health and health care data. We can only use the data that actually is collected and currently, demographic data is often not collected universally or pursuant to

standardized categories. We urge HHS to include a bullet addressing the collection of health and health care data as follows:

- ***Improve collection of health and health care data by race, ethnicity, language, sex, gender identity, sexual orientation, age and disability. Race and ethnicity data should be disaggregated. Health and health care data should be collected pursuant to recommendations made by the Institutes of Medicine.***

ii. **Incentivize safe, high-quality care, Line 242**

Under this strategy, one bullet mentions the desire to expand opportunities for alternative payment models in Medicaid and Medicare. While we support innovations to promote the provision of high-quality care, we note that alternative payment models must not be implemented in such a way that they create incentives to stint on needed care or avoid costlier patients. We believe that HHS should focus on models that prioritize primary care (for example, that include strong PCMH requirements), and which do not use financial incentives premised on the total cost of care, which can readily result in such stinting. Putting financial risk on provider and provider groups, while potentially motivating a reduction in total outlays (although the evidence for this is scant as well) is not likely to result in improved quality. Further, quality measures often developed to act as a check on saving money through stinting are inherently inadequate to address all the ways in which providers may inappropriately cut costs, consciously or unconsciously. We recommend that if HHS uses any financial incentives, those incentives should be focused on improving outcomes and not on reducing costs; one such recommended approach is to pay primary care providers extra for keeping their patients out of ERs and avoiding repeat hospitalizations. Finally, “paying for value” should be readily acknowledged to have been accomplished where total costs remain the same but the quality of care is substantially increased, in that the state or other payer is then receiving substantially more for the same dollars, a result which should be encouraged.

We appreciate HHS’ recognition that preventive services should be available in community-based settings. We believe additional services should also be available in community based settings, particularly home and community based services (HCBS) provided through Medicaid. We thus recommend amending the relevant bullet as follows:

Line 251

- Help beneficiaries access ~~preventive~~ **all** care in community-based settings, while encouraging innovation and competition through use of performance-based payment

iii. **Empower patients, families, and other caregivers to facilitate the delivery and increase the use of safe, high-quality, person-centered care, Line 275**

We appreciate the recognition of the need to provide programs that improve the quality of care and increase access. To that end, we recommend that such programs be developed and implemented in a culturally competent manner. We thus recommend amending the relevant bullets as follows:

Lines 277-282

- Expand the engagement of patients, families, and other caregivers in developing and implementing **culturally competent** programs that improve the quality of care and increase access to services available to them
- Promote the development, implementation, and use of **culturally competent** experience and outcome measures, including patient-reported data and price transparency data, as appropriate, for use in quality reporting

iv. **Reduce disparities in quality and safety, Line 283**

We strongly support the inclusion of this strategy as it is critical to ensure that our health care system is accessible to all individuals, regardless of race, ethnicity, language, immigration status, sex, gender identity, sexual orientation, age and/or disability. We believe all of these strategies must be kept and indeed should be expanded upon.

We also recommend that to the extent HHS recognizes the need for providing materials in non-English languages that it also recognize the need for providing materials in formats that will be accessible to individuals with disabilities who have communication needs. This would include large print format and audio or video recordings for those who cannot access written materials. We recommend amending the relevant bullet as follows:

Line 294

- Increase available information in cultural- and health literacy-appropriate levels, and in alternate formats, — such as in languages other than English, **large print, or audio and video versions** — to improve access to health information

v. **Collect, analyze, and apply data to improve access to safe, high-quality health care, Line 299**

As we mention above, we support increased demographic data collection to ensure that data can be stratified and analyzed by a variety of factors to identify, and then address, health and health care disparities. Similarly, we support this section but recommend adding specific language regarding the collection of **demographic** data as follows:

Line 300

- Collect additional **demographic** data (**including race, ethnicity, language, sex, gender identity, sexual orientation, age and disability**), identify barriers to access, facilitate consumer engagement and promote evidence-based practices, to improve access to physical and behavioral health services
- Measure and report on healthcare quality and disparities at the national, state, local, and individual provider level to facilitate improvement in the healthcare system; **to the maximum extent possible, measures and reports on disparities data should be disaggregated**

C. **Strategic Goal 1, Objective 1.3**

i. **Improve consumer understanding of healthcare options and consumer-directed healthcare decisions, Line 337**

We appreciate the recognition of the need to improve understanding of healthcare options. As we have mentioned previously, we believe this must be done in a culturally competent manner. We thus recommend the following changes to the strategies listed in this section:

- Promote information and assistance that is **culturally competent**, accessible, transparent, and provided in understandable formats (**including non-English languages for limited English proficient individuals and alternative formats such as large print and audio and video options for individuals with disabilities**) to ensure care and insurance options meet patient needs
- Expand **culturally competent** communication and coordination within communities to enable communities to identify community needs and more effective approaches to improve delivery of healthcare services

ii. **Design healthcare options that are responsive to consumer demands, while removing barriers for faith-based and other community-based providers, Line 353**

We are concerned that this section fails to mention other federal civil rights laws and Executive Orders which are relevant to providing healthcare options that are responsive to consumer demands. These include Executive Order 13166, Title VI of the Civil Rights Act of 1964, Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, the Age Discrimination Act, and Section 1557 of the Affordable Care Act. All of these laws must be fully implemented and enforced by HHS to ensure that HHS' programs and activities, and those it supports with federal funds, are responsive to consumer demands. We thus recommend adding the following bullet:

- ***Vigorously enforce laws, regulations and other authorities, especially Title VI of the Civil Rights Act of 1964, Executive Order 13166, Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, the Age Discrimination Act, and Section 1557 of the Affordable Care Act***

iii. **Reduce disparities in access to health care, Line 380**

We strongly support the inclusion of this strategy as it is critical to ensure that our health care system is accessible to all individuals, regardless of race, ethnicity, language, immigration status, sex, gender identity, sexual orientation, age and/or disability. We believe all of these strategies must be kept and indeed should be expanded upon. We also strongly support the bullet reaffirming the need to remove barriers to inclusion and accessibilities for individuals with disabilities.

We recommend the following changes to the relevant bullets.

Lines 381-393

- Test ***culturally competent*** patient-centered models of care, including patient-centered medical home recognition and care integration, and support the adoption and evolution of such models that reduce expenditures ~~and~~ ***only if they*** improve quality of care
- Support research to provide evidence on how to ensure ***culturally competent*** access to affordable, physical, oral, vision, behavioral, and mental health insurance coverage for children and adults
- Provide ***culturally competent*** resources and tools to providers and plans to encourage implementation of ***culturally competent*** activities and strategies to help improve healthcare access

D. ***Strategic Goal 2, Objective 2.1***

We support the recognition in this objective that HHS should focus on certain populations, including populations at risk for poorer health outcomes including older adults, people with disabilities, racial and ethnic minorities, American Indian and Alaska Native populations, people with low socioeconomic status, and people with limited English proficiency. We do not, however, agree with HHS' statement that removing barriers to and promoting participation in HHS programs by persons and organizations with religious beliefs or moral convictions is a solution. Rather, HHS should remain religiously and morally neutral in its funding and activities to ensure that individuals do not feel proselytized by providers or receive access to a limited scope of services due the moral or religious nature of an organization.

i. **Ensure People have the information they need to make healthier living choices, Line 488**

We support the information in this section but recommend that HHS include additional information about legal requirements regarding effective communication. The third bullet (line 497) **encourages** providers to communicate effectively with patients, family and caregivers (emphasis added). However, a number of civil rights statutes – including Title VI of the Civil Rights Act, Section 504 of the Rehabilitation Act, Section 1557 of the Affordable Care Act – provide actual requirements for effective communication. It should be part of HHS’ plan to ensure that providers subject to these laws do more than “encourage” effective communication. We thus recommend rewriting that bullet as follows:

Line 497

- Encourage **Ensure** providers **comply with federal civil rights requirements** to communicate effectively with patients, families, and caregivers by offering tools and resources to assist discussions centered around care and healthier living

We appreciate the inclusion of strategies to promote healthcare access and reduce disparities under this objective although we recommend deleting the specific mention of “faith-based” in the last bullet.

E. Strategic Goal 2, Objective 2.4

i. **Promote emergency preparedness and improve response capacity, Line 761**

We appreciate the role HHS has in preparing for and responding to public health emergencies. We believe that much of this work, especially in the provision of tools to states and providing public health communications must be done in a culturally competent manner. Too often, certain population groups are overlooked in public health preparedness. We have seen this in Texas and Louisiana when public health communications are not provided in Spanish, Korean or other languages and thus individuals with limited English proficiency are left out of warning systems or post-emergency assistance and recovery efforts. As recognized by Objective 2.1 above, certain populations are at risk for poorer health outcomes including older adults, people with disabilities, racial and ethnic minorities, American Indian and Alaska Native populations, people with low socioeconomic status, and people with limited English proficiency. Thus HHS’ tools and communications should include specific consideration of the needs of these groups. We recommend HHS include additional bullets and amend certain bullets under this section as follows:

- **Ensure tools are culturally competent and address populations are at risk for poorer health outcomes including older adults, people with disabilities, racial**

and ethnic minorities, American Indian and Alaska Native populations, people with low socioeconomic status, and people with limited English proficiency

- **Ensure public health communications are culturally competent and address populations are at risk for poorer health outcomes including older adults, people with disabilities, racial and ethnic minorities, American Indian and Alaska Native populations, people with low socioeconomic status, and people with limited English proficiency**

Line 768

- Develop and implement data-driven approaches that prioritize resources and technical support for under-prepared geographical regions and communities to maximize preparedness across the nation **and that collect data on race, ethnicity, language, sex, gender identity, sexual orientation, and disability status so that tools, communications and responses can be appropriately targeted**
- ii. **Improve collaboration and communications with federal and State, Local, Tribal and Territorial partners, Line 793**

We support the recognition of the need to improve collaboration with State, Local, Tribal and Territorial (SLTT) partners. We recommend that these strategies also specifically recognize the need to provide information in a culturally competent manner.

Line 795-803

- Provide accurate, **culturally competent**, and timely public health communication and media support to stakeholders and leadership, including deployed HHS leaders and teams
- Work with partners to develop, exercise, update and maintain **culturally competent** risk communication, response, and recovery plans

F. Strategic Goal 5, Objective 5.3

We support the objective to optimize information technology investments to improve process efficiency and enable innovation to advance program mission goals. As part of HHS' goal is to reduce healthcare disparities, as mentioned throughout earlier sections in the report, we believe HHS should ensure that efforts to identify and address healthcare disparities are sufficiently recognized and address with regard to information technology investments.

All HHS data systems that are built or upgraded must include the ability to collect and analyze demographic data. This should include applicant/enrollee data but also provider

data. Without accurate and comprehensive data, HHS will be unable to identify healthcare disparities. This data must widely collected and include data on race, ethnicity, language, sex, gender identity, sexual orientation, age, and disability status. Further, the data must be disaggregated as much as possible so that subgroup disparities are not masked if only identified by larger groupings. For example, Vietnamese women are at a much higher risk of cervical cancer but if cancer data is only collected or reported by “Asian and Pacific Islander” rather than the disaggregated category of “Vietnamese” one might not be able to identify the differences among various Asian and Pacific Islander subgroups.

Section 4302 of the Affordable Care Act (ACA), adding section 3101 to the Public Health Service Act, requires the Department of Health and Human Services (HHS) to ensure that certain data is collected throughout all HHS programs, activities and surveys. In particular, it requires that data be collected on race, ethnicity, primary language, sex, and disability status. It also permits the Secretary to extend this requirement to any other demographic data regarding health disparities. To implement this section, HHS must determine the scope of this provision (specifically to what and whom the new data collection requirements apply), what standards should be used to collect this data, and what, if any, other demographic categories should be required for collection.

The collection of high quality data in quantities sufficient for study is a critical first step in understanding and eliminating disparities in health outcomes and access. While the existence of health disparities in the U.S. has been well documented, the reasons for these disparities still are not fully understood. In part, this is due to a lack of high quality, easily available data. For example, data on smaller racial and ethnic groups is often not robust enough to lend itself to meaningful analysis. Similarly, data is often not available for intersecting subpopulations that might experience multiple barriers to access, such as Latinas who have disabilities or transgender individuals with limited English proficiency.

The need for better data is clearly articulated by a variety of researchers studying health disparities. For example, a recent report on health disparities in the U.S. by the Centers for Disease Control and Prevention (CDC) cites a lack of sufficient data, especially with respect to disability status and sexual orientation, as a limitation of the report¹⁵. The need for better data collection was also the subject of a 2004 publication of the Committee on National Statistics entitled *Eliminating Health Disparities: Measurement and Data Needs*.¹⁶

In addition to identifying disparities, high quality data is critical to addressing these disparities. Data can help researchers, policy makers, public health workers, and health care practitioners target interventions to the populations that need them most and tailor

¹⁵ U.S. Department of Health and Human Services. Centers for Disease Control and Prevention. *CDC Health Disparities and Inequalities Report*. Atlanta, GA: 2011. <http://www.cdc.gov/mmwr/pdf/other/su6001.pdf>.

¹⁶ National Research Council of the National Academies. Committee on National Statistics. *Eliminating Health Disparities: Measurements and Data Needs*. Washington: National Academies Press, 2004. <http://www.nap.edu/openbook.php?isbn=0309092310>.

interventions to the specific needs of a community. Further, health disparities data collection is crucial for measuring quality. Such information is integral to understanding if a particular program is improving the health outcomes of all groups. Without this data, average improvement in the health outcomes could mask a lack of improvement or even worsening in outcomes for a specific population. Therefore, it is crucial for demographic data to be collected in sufficient quantities, in a variety of health care settings, and at multiple levels of geographic detail.

We recommend the addition of the following bullets in this objective:

- ***Ensure that all data collection systems operated or funded by HHS collect, at a minimum, disaggregated data regarding race, ethnicity, primary language, sex, and disability status***
- ***Ensure that all data collection systems operated or funded by HHS have sufficient privacy protections and electronic safeguards to prevent the unauthorized access, use, or disclosure of demographic and other data***

V. Implications for LGBT Individuals

LGBT people are considered a vulnerable population as it concerns their health. LGBT people face higher rates of HIV/AIDS, depression, an increased risk of some cancers, and are twice as likely as their heterosexual peers to have a substance use disorder.^[2]

Transgender people in particular are at higher risk for a range of poor health outcomes. For example, the 2015 U.S. Transgender Survey, a national study of nearly 28,000 transgender adults, found that respondents were nearly five times more likely to be living with HIV than the general population, with even higher rates for some populations: for example, nearly one in five (19%) Black transgender women living with HIV, more than 63 times the rate in the general population. Transgender respondents were nearly eight times more like than the general population to be living with serious psychological distress based on the Kessler 6 scale, with higher rates correlating with experiences of discrimination, violence, and rejection. The medical community and scientific research has repeatedly demonstrated that the poor health outcomes that LGBT people face are not associated with any inherent pathology, but rather high rates of poverty, discrimination in the workplace, schools, and other areas, and barriers to nondiscriminatory health care that meets their needs.

Recognizing these disparities and the impact they have on LGBT people, improving the health, safety, and well-being of LGBT people was made a goal of Healthy People 2020. LGBT people were included in a number of other health objectives including mental health and mental illness, tobacco use, usual source of care, and health insurance coverage, and the National Institute of Health (NIH) formally designated sexual and gender minorities as a health disparity population in 2011 for NIH research.¹⁷

¹⁷ Kellan Baker, "Open Doors for All" (Washington: Center for American Progress, 2015), available at <https://www.americanprogress.org/issues/lgbt/reports/2015/04/30/112169/open-doors-for-all/>.

A major factor in these health disparities is the discrimination that LGBT people face when trying to access health care. While the Affordable Care Act has significantly increased the percentage of LGBT people with insurance and has helped prohibit discrimination against LGBT people in coverage and care, LGBT people are still more likely than non-LGBT adults to lack insurance and LGBT people still face discrimination.¹⁸ A recent survey by found that transgender respondents were over 5 times more likely to avoid doctor's offices just to avoid the risk of experiencing discrimination than their cisgender counterparts.¹⁹ Additionally, the 2015 U.S. Transgender Survey found that, just in the past year, 33% of those who saw a health care provider face some form of mistreatment or discrimination because of being transgender, such as being refused care, harassed, or physically or sexually assaulted, and 23% avoided seeing a doctor when needed due to fear of discrimination. We expect HHS to continue serving LGBT people and believe the strategic plan is an ideal opportunity for HHS to show that it plans to engage in targeted efforts to ensure that vulnerable populations like LGBT communities get the healthcare they need.

As a population that experiences the significant disparities related to health care access, essential services, and economic security described above, LGBT individuals should be specifically mentioned in relevant portions of the Strategic Plan. In previous strategic plans, HHS included explicit references to the LGBT population when discussing goals related to providing access to quality, competent care, improving data collection, supporting the healthy development of youth, and expanding access to culturally competent services, among other goals. We recommend that the needs of the LGBT population be explicitly mentioned in some of the following key goals:

- Collect additional data, identify barriers to access, facilitate consumer engagement, and promote evidence-based practices to improve access to physical and behavioral health services
- Measure and report on healthcare quality and disparities at the national, state, local, and individual provider level to facilitate improvement in the healthcare system
- Identify individuals and populations at risk for limited health care access and assist them to access health services, including prevention, screening, linkages to care, clinical treatment, and relevant support services, including through mobilization of faith-based and community organizations
- Health promotion and wellness strategies supported by HHS are often focused on specific populations at risk for poorer health outcomes, such as older adults, people

¹⁸ Kellan Baker, Sejal Singh, Shabab Ahmed Mirza, and Laura E. Durso, "The Senate Health Care Bill Would Be Devastating for LGBTQ People" (Washington: Center for American Progress, 2017), available at <https://www.americanprogress.org/issues/lgbt/news/2017/07/06/435452/senate-health-care-bill-devastating-lgbtq-people/>.

¹⁹ Sejal Singh and Laura E. Durso, "Widespread Discrimination Continues to Shape LGBT People's Lives in Both Subtle and Significant Ways" (Washington: Center for American Progress, 2017), available at <https://www.americanprogress.org/issues/lgbt/news/2017/05/02/429529/widespread-discrimination-continues-shape-lgbt-peoples-lives-subtle-significant-ways/>.

with disabilities, racial and ethnic minorities, American Indian and Alaska Native populations, people with low socioeconomic status, children, and people with limited English proficiency

- Produce and promote patient-centered health care delivery methods and interventions that improve care quality, promote healthcare access, reduce disparities, and address social determinants of health among populations at risk for poor health outcomes
- Support research to identify, implement, and evaluate interventions to reduce health disparities and improve the health of populations at risk for poor health outcomes

It is our request that the plan be revisited taking into consideration a large body of research demonstrating the need for specific and competent inclusion of LGBT people in all aspects of efforts to improve the health of Americans.

VI. Impact on People with Substance Use Disorders

We appreciate HHS' recognition of the importance of expanding the entire spectrum of interventions, from prevention through recovery, as well as the importance of public health approaches to preventing, identifying, and treating substance use disorders. We also support the emphasis on a collaborative approach that involves both governmental and non-governmental organizations. We caution, however, that some faith-based and "community" organizations rely on outdated and non-evidence-based approaches to mental and substance use disorders, many of which do not reduce the incidence and prevalence of these disorders and some of which can be harmful to vulnerable individuals and communities.

We urge HHS to engage in education and outreach to ensure that both governmental and non-governmental organizations are aware of and are utilizing modern, evidence-based, non-stigmatizing approaches to substance use disorders. We also urge HHS to ensure that "community" organizations are inclusive of people who use drugs (PWUD), including harm reduction organizations.

i. Expand prevention, screening, and early identification of serious mental illness and substance use disorders

We recommend removing the word "serious" from this heading. It is not defined, and there is real value in early prevention, screening, and identification of even "non-serious" mental illness and substance use disorders.

Line 658:

- Educate and empower individuals and communities, including through partnerships with faith-based, ***harm reduction***, and community organizations, to recognize the

signs of ~~serious~~ mental illness and substance use disorders, to encourage screening and identification of such problems

Line 661:

- Ensure early screening of children and youth to identify those with or at risk for ~~serious~~ emotional disturbance and substance use disorders, and expand access to integrated, **evidence-based** mental health and substance use disorder services

Line 666:

- Support screening for depression, suicide risk, substance **misuse**, overdose risk, and other behavioral disorders in schools, emergency departments, and inpatient and outpatient settings

Line 674:

- Increase **evidence-based** school- and community-based primary prevention programs, ~~including through faith-based and community organizations,~~ that integrate risk and protective factors for mental health and substance use disorders among youth
- ii. **Improve access to high-quality care and treatment for mental and substance use disorders**

Line 683:

- Provide integrated child and family supports to parents/guardians with, **at risk for, and in recovery from** substance use disorders to support healthy child development, **improved parental outcomes**, and that families remain intact

Line 685:

- Improve access to **medication assisted treatment and** medications that reverse opioid overdose and prevent death and support **non-coercive** efforts to increase engagement in treatment following an opioid overdose

Add new bullet:

- ***Work with states to expand and improve access to substance use disorder services for low-income populations by implementing innovative approaches to prevention and treatment through the Medicaid program***

iii. **Improve access to recovery support for people with serious mental illness and substance use disorders**

Line 690:

- Expand ***and improve the quality and effectiveness of*** the peer provider workforce by working with states to increase the training, certification, financing, and supervision of peers

Line 694:

- Engage individuals and communities, including through faith-based, ***harm reduction***, and community organizations, to provide ***evidence-based, non-judgmental*** social and community recovery support

iv. **Build capacity and promote collaboration among states, tribes, and communities**

Line 703:

- Foster and strengthen relationships with faith-based, ***harm reduction***, and community partners to encourage their full and robust involvement in addressing the opioid crisis in their local communities by providing accurate, up-to-date information regarding health and human service activities, resources, and subject matter expertise; and by strengthening national, regional and local coalitions

v. **Invest in evaluation and promote evidence-based interventions**

Line 718:

- Improve adoption and continued refinement of ~~selected~~ evidence-based practices for ~~serious~~ mental illness, medication assisted treatment for opioid use disorder, and effective use of psychotherapy and antidepressant medication for depression

vi. **Leverage technology and innovative solutions**

Add new bullet:

- ***Support access to evidence-based substance use disorder care for rural and underserved populations by removing barriers to the implementation of mobile-based medication-assisted treatment for opioid use disorder***

VII. **Additional Comments**

A. Strategic Goal 1, Objective 1.1

We appreciate the outline of this objective and many of its specifics. However, we believe HHS' strategic plan must specifically mention and address HHS' legal responsibility to uphold the laws of the United States, including the Affordable Care Act and Medicaid. Without robust implementation of the ACA and adherence to Medicaid's governing statute and regulations, many of the goals and strategies outlined in this plan will be unobtainable. Further, we appreciate the recognition that consumers and enrollees should have choice but that choice must come with sufficient knowledge and information to make informed choices. The recent actions by the Administration to cut funding for navigators and open enrollment outreach are contrary to the stated ability to provide consumers with choices that they actually can understand. Navigators in particular play a critical role in informing consumers about their eligibility for health insurance, helping them enroll, explaining how to use health insurance, and connecting them with health care.

We thus suggest adding a new "strategy" bullet that would read as follows:

Implement and enforce the ACA

- ***Ensure sufficient resources to maintain and improve healthcare.gov and its Call Center.***
- ***Provide sufficient financial support to FFM navigators to ensure they can operate in all counties in all FFM states and throughout the entire calendar year.***
- ***Conduct outreach activities commensurate with the need to educate and inform individuals about the marketplaces, public health insurance programs (including Medicaid, CHIP and Medicare), their health insurance options, and how to enroll.***
- ***Ensure compliance with all statutory and regulatory requirements regarding the Affordable Care Act and Medicaid.***

B. Strategic Goal 1, Objective 1.3

i. Expand coverage options, Line 325

We appreciate the recognition of needing to increase plan choice in Medicare. However, we are concerned that the strategic plan seems to assume that reducing "administrative, regulatory, and operational burdens" will achieve this goal. HHS must ensure that any steps to reduce these burdens do not erode the important beneficiary protections imbedded in Medicare.

We recommend the same strategy should be included regarding marketplace plans. HHS has taken a number of steps in recent months that has led to instability in the marketplaces and reduced the number of participating insurers while raising costs. This includes cutting

of cost-sharing payments, reducing navigator funding by over 40%, reducing outreach funding by 90%, and shortening the open enrollment period. Given its legal responsibility to uphold the laws of the United States, we strongly believe HHS should take pro-active, positive steps to increase plan choice in the marketplaces. HHS could commit to funding cost-sharing reductions throughout the strategic plan's time period, increase the length of open enrollment, restore funding to FFM navigators and for outreach, and ensure all systems, policies, processes and regulations regarding the ACA are fully implemented and enforced. We recommend adding the following bullet to this section:

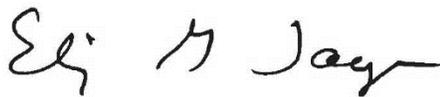
Line 326

- ***Expand plan choice in the marketplaces by fully complying with requirements outlined in the Affordable Care Act and protecting the integrity and soundness of federal and state marketplaces***

VI. Conclusion

Thank you for your attention to our comments. If you have any questions or need any further information, please contact Mara Youdelman, Managing Attorney (youdelman@healthlaw.org; (202) 289-7661).

Sincerely,

A handwritten signature in black ink that reads "Elizabeth G. Taylor". The signature is written in a cursive, flowing style.

Elizabeth G. Taylor
Executive Director