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LEGISLATIVE OFFICE

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Office of the Assistance Secretary for Planning and Evaluation
Strategic Planning Team
Department of Health and Human Services
200 Independence Ave. S.W.
Room 415F
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VIA ELECTRONIC MAIL – HHSPlan@hhs.gov

Attn: Strategic Plan Comments

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The American Civil Liberties Union ("ACLU"), on behalf of our more than two million members and supporters, submits these comments to the Department of Health and Human Services ("The Department" or "HHS") on its draft Strategic Plan for Fiscal Years 2018-2022 ("Strategic Plan").

We have organized our comments by thematic area, including an overview of the Strategic Plan's expansive view of the role of religion in healthcare and the discriminatory effect on LGBTQ people and women; its troubling implications for reproductive healthcare; its failure to identify specific populations most affected by health disparities; and detailed implications for community integration for people with disabilities.

HHS has a statutory obligation to submit a Strategic Plan describing the agency's plan to address evolving health and human services issues,[1] but we are concerned that the proposed Strategic Plan constitutes a harmful departure from past plans. The plan prioritizes ideology over equal access to health care and will enshrine an approach at HHS that permits the use of religion to discriminate, particularly against women and LGBTQ people. We are also concerned that the Strategic Plan indicates that HHS will erect even more barriers to reproductive healthcare access.

However, we were pleased to note that HHS addresses issues related to individuals with disabilities throughout the plan, recognizing that accessibility, community-integration and self-determination are implicated in almost every aspect of health care. Our comments below seek to strengthen and clarify HHS's strategies, particularly as they relate to access to community life for people with disabilities. For those sections we have suggested edits and additional language (in bold) to the Strategic Plan.

[1] This statutory obligation is created by the Government Performance and Results Act (GPRA) of 1993 (P.L. 103-62) and the GPRA Modernization Act of 2010 (P.L. 111-352).

I. The Strategic Plan Expands the Use of Religion to Discriminate Against LGBTQ People and Women

HHS's overarching mission and function is "to enhance and protect the health and well-being of all Americans." However, this plan is packed with language that would undermine that very goal by allowing the use of religion to discriminate, particularly against LGBTQ people and women.

In Objective 1.3, the plan suggests that a primary strategy is to "[remove] barriers for faith-based" providers. It states that HHS will "promote equal and nondiscriminatory participation by faith-based organizations in HHS-funded or conducted activities" and "affirmatively accommodate" burdens imposed on the exercise of religious beliefs and "moral convictions" by persons and entities partnering with HHS. This language improperly implies that limitations on health care access may be appropriate based on religious or moral grounds. That is incorrect. One individual's personal religious beliefs or "moral convictions" should never determine or limit the health care that another individual can receive. When hospitals, clinics, and individual health care providers have the ability to refuse patient care based on religious beliefs or "moral convictions," patients may suffer devastating health consequences.[2]

Also under this Objective, the Strategic Plan states HHS should "vigorously enforce" and implement Executive Order 13798, "Promoting Free Speech and Religious Liberty." This Executive Order, signed by President Trump in May, did nothing more than lay a foundation for discrimination against LGBTQ people, women and religious minorities under the guise of religious liberty. We find it appalling that HHS has apparently adopted the Executive Order's directive to explore religious-based exceptions to health care, particularly because the Strategic Plan does not mention other federal civil rights laws and Executive Orders which are relevant to providing health care. These include Section 1557 of the Affordable Care Act, Executive Order 13166, Title VI of the Civil Rights Act of 1964, Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, and the Age Discrimination Act. Requiring that all taxpayer-funded organizations, including those that are religiously affiliated, provide unbiased, non-discriminatory, evidence-based information and services is not a "barrier" to be removed, but rather a consumer and patient protection to be upheld.

Further, this Strategic Plan includes no objectives or strategies for LGBTQ individuals, who already face multiple barriers to care. In fact, the plan makes no reference to LGBTQ people at all, a shameful omission. Instead, the Strategic Plan prioritizes the inclusion of faith-based organizations that often engage in discriminatory actions in programming and education relating to LGBTQ young people. This undermines the ability of young people 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

[2] 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).

the confidentiality of services and counseling that young people 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.

II. The Strategic Plan Undermines Access to Reproductive Healthcare

We are also very concerned that HHS has added multiple references to "the unborn" and life beginning "from conception" to its plan. This language, which runs contrary to medical evidence, standards of care, and well established constitutional case law, is clearly intended to undermine the ability of women and others to make the best reproductive health decisions for themselves and their families. This language has no role in advancing and protecting the public health of a diverse population.

In its 1973 decision in *Roe v. Wade*, which established abortion as a fundamental right for women, the Supreme Court declared that "the word 'person,' as used in the Fourteenth Amendment, does not include the unborn."[3] This central holding of *Roe* has been consistently upheld and reaffirmed by the Supreme Court for more than 40 years, including just last year in *Whole Woman's Health v. Hellerstadt*.[4] The language in the Strategic Plan is an attempt to directly undermine this fundamental right by asserting an unconstitutional definition of personhood as beginning at conception.

HHS's reliance on these terms raises serious concerns about government overreach into the provider-patient relationship and threatens women's access to crucial health care services, including birth control, assisted reproductive technology (ART), stem cell research, and *in vitro* fertilization (IVF). Perhaps most crucially, this unconstitutional non-medical definition threatens autonomous decision-making for all pregnant people, including those intending to carry their pregnancies to term. This is an unacceptable and unconstitutional infringement on a woman's autonomy over her own body.

We need look no further than the case of "Jane Doe," a 17-year-old immigrant in the care of HHS' Office of Refugee Resettlement (ORR), to understand what the Strategic Plan looks like in action. Jane, who is being held at a government-funded shelter in Texas, decided to have an abortion in September, but was forced by HHS to carry the pregnancy against her will for over a month while HHS fought in court to block her from accessing care. She secured her own funding, obtained a judicial bypass as mandated by state law, and arranged transportation through her court-appointed guardian and attorneys. However, ORR went to extraordinary lengths to prevent her from accessing constitutionally-protected care, including blocking her from traveling to appointments, and forcing her to visit a so-called "crisis pregnancy center," where non-medical personnel made Jane undergo and view a sonogram against her wishes. ORR effectively held Jane hostage to the detriment of her health and rights. And yet, according to an HHS statement, the Department believes that it was "providing excellent care to this young

[3] *Roe v. Wade*, 410 U.S. 113 (1973)

[4] *Whole Woman's Health v. Hellerstedt*, 136 S. Ct. 2292 (2016)

woman and her unborn child." These are the kinds of unconscionable actions we can expect to flow from HHS's current Strategic Plan.

III. The Strategic Plan Fails to Identify Specific Populations Most Affected by Health Disparities

The current HHS Strategic Plan for FY2014-2018 establishes specific measurable goals to improve the health outcomes of all Americans by specifically recognizing the health disparities that persist among populations, including racial and ethnic minorities, individuals with disabilities, refugees, lesbian, gay, bisexual, and transgender (LGBTQ) individuals.[5] To give just one example of stark health disparities that exist in the United States, black women are three to four times more likely to die from pregnancy complications than white women are, and they are twice as likely to suffer maternal morbidity.[6] The 2014-2018 Plan recognizes and highlights the need for active efforts to reduce existing disparities among specific populations and to ensure that the most vulnerable populations within the United States receive access to health care. Furthermore, the 2014-2018 Plan details a data-driven agenda to support research that will increase our understanding of population subgroups such as racial and ethnic minorities, the re-entry population, and LGBTQ populations.

In contrast, while the Strategic Plan promotes "culturally-competent care" and recognizes that health disparities exist generally, it removes all language identifying these communities and sub-populations specifically by name. At best, this makes the objectives and goals with the Strategic Plan less measurable and meaningful; at worst, these omissions indicate that the agency will deprioritize work on closing gaps in health care services and outcomes across these groups. We strongly urge HHS to include, as it has in the past, specific objectives and goals relating to the persistent health disparities that continue to exist for ethnic and racial minorities, individuals with disabilities, refugees, LGBTQ individuals, and re-entry populations.

IV. The Strategic Plan Must Ensure Non-Discrimination for People with Disabilities

People with disabilities frequently face significant discrimination in access to health care, ranging from inaccessible health care facilities and inaccessible medical equipment, to inadequate communication access, to the withdrawal or refusal of life-sustaining treatment due to inaccurate perceptions about the quality of life for people with significant disabilities. We appreciate HHS referencing the importance of including people with disabilities in public health programs, and believe that the increased presence and visibility of people with disabilities in the public health workforce represents one important aspect in mitigating these problems. In addition, we believe that HHS has a vital role to play in promoting a proactive agenda of disability non-discrimination and urge the Department to include this as a robust component

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

[6] CENTERS FOR DISEASE CONTROL AND PREVENTION, *Reproductive Health: Pregnancy Mortality Surveillance System*, (last updated June 29, 2017), https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pmss.html; Andrea A. Creanga et al., *Racial and Ethnic Disparities in Severe Maternal Morbidity: A Multistate Analysis*, 2008-2010, 210 AM. J. OBSTET. GYNECOL. 435, 437 (2014).

within its Strategic Plan. We encourage HHS to make use of the Protection and Advocacy system, administered by the Administration for Community Living (ACL), to accomplish this goal. Our suggested edits to the plan are below.

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.***

Line 399-403

- 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 health care providers ***with disabilities ~~or religious beliefs or moral convictions~~***, to collecting and analyzing data for continuous improvements.

Insert after line 412

- ***Support the training, recruitment, placement and retention of medical professionals with disabilities, through grants, student loan repayment, and other education incentives, to expand the pool of qualified healthcare providers with direct experience with and knowledge of physical and mental disabilities.***

Line 978

- Address data gaps in prevalence and risk factors for child maltreatment***, including the inappropriate withdrawal of life-sustaining treatment from children with disabilities, and invest in models for prevention and intervention.***

V. The Strategic Plan Must Promote Community Integration for People with Disabilities

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. We urge HHS to continue to enforce the HCBS Settings Rule issued by the Center for Medicare and Medicaid Services in 2014, and encourage enforcement to be referenced as an explicit priority within the Strategic Plan.

With reference to HHS's administrative structure, we approve of the continued reference to ACL as a key component of implementing this Strategic Plan. The creation of ACL represented an important and valuable development for the disability community with the potential to improve the administration of disability and disability-relevant programs throughout HHS. We urge HHS to ensure that ACL continue to play a vital role in disability-relevant policy deliberations, even when they occur elsewhere within HHS. For example, ACL staff possess vital expertise in long-

term services and supports and should be considered an ongoing resource to CMS on the design and administration of Medicaid-financed long term services and supports to seniors and non-elderly people with disabilities. We also urge HHS to affirm the importance of non-elderly people with disabilities in ACL's leadership and mission.

HHS's 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 swaths of facilities, including juvenile detention facilities, homeless shelters, jails and prisons, for the purposes of addressing abuse, neglect and rights violations. HHS should ensure that the rights of individuals are protected in all appropriate settings.

Finally, protection from abuse and neglect must also 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, including those with disabilities, in psychiatric hospitals until the storm passed. While all individuals should be able to seek shelter, involuntary commitment is not the solution, particularly when serving the needs of individuals with psychiatric disabilities. Instead, we hope that HHS prioritizes strategies that incorporate 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. Our suggested edits to the plan are below.

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***.

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 help individuals live in integrated settings.***

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, ***including individuals with limited mobility or special health needs,*** are met in emergencies, through effective integration of traditionally underserved populations into planning, response, and recovery efforts.

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 *the****ir own homes and communities, in the most integrated setting appropriate to their needs, with opportunities for active community and workforce participation.*** ~~***community***~~

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 offers the greatest opportunities for active community and workforce participation***.

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 provide the greatest opportunities for active community and integrated workforce participation.***

Lines 1090-1092

- Support the development of endorsed performance measures to include a HCBS core set to measure and quantify processes and outcomes, and enable comparable data for public reporting and quality measurement, ***with a specific emphasis on encouraging greater community integration and self-determination within the spectrum of HCBS models and provider choices.***

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 and workforce participation, including by supporting states to fully comply with the CMS HCBS Settings Rule by 2022.***

Lines 1110-1112

- Expand the availability of, and access to, supports for unpaid family caregivers, to maximize the health and well-being of the caregivers and the people for whom they provide care***, including through the expansion of in-home respite, shared living/host homes and other targeted services to support individuals with disabilities continuing to live in family homes.***

To Insert in Line 1136

- ***Grow the size and quality of the direct support workforce assisting individuals with disabilities in home and community based service models by investing in better training, higher wage rates and expanding the use of budget authority self-directed service models, allowing individuals with disabilities to select their own workers and negotiate their pay.***

VI. The Strategic Plan Must Protect the Parenting Rights of People with Disabilities

Parents with disabilities face significant discrimination within the child welfare system, a fact that HHS acknowledged in its October 2016 joint guidance with the Department of Justice on "Protecting the Rights of Parents and Prospective Parents with Disabilities." Parents with disabilities often face inappropriately high rates of removal and loss of custody due to inaccurate perceptions of their ability to parent, which are borne out of stereotypes associated with their disability. HHS should make addressing this an important component of its Strategic Plan. We have included suggested edits below:

Insert New 1016

- **Support parents with disabilities through the delivery of appropriate adaptive equipment and instruction, targeted services and robust enforcement of the Americans with Disabilities Act with relation to child welfare systems, adoption agencies and state family courts.**

VII. The Strategic Plan Must Promote Supported Decision-Making

Supported decision-making is a growing model that enables people with disabilities to exercise legal capacity with support, rather than surrender their legal capacity through guardianship or conservatorship or go without recognized assistance in decision-making. Multiple state legislatures have adopted supported decision-making laws, and principles of supported decision-making are reflected within numerous federal regulations, such as the HCBS Settings Rule. We suggest revisions to the following strategies to prioritize supported decision-making and the broader related 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 supported 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.***

We appreciate HHS's acknowledgement that requests to relax HIPAA to make it easier to share medical information may be based on 'perceived barriers' on sharing information than actual limits. We believe HIPAA already permits sufficient flexibility to communicate health information without relaxing it further. It is our position that it would be inappropriate to expand that flexibility to allow any additional disclosure of protected health information in a manner not authorized by the individual with a disability.

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 served, 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 **voluntary** 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 voluntary strategies that avoid***

coercion and depend on the consent of the individual with a disability, 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 for both seniors and non-elderly people with disabilities.***

For the above reasons, while the ACLU appreciates and recognizes HHS's efforts to incorporate disability interests in its strategic plan, we also have serious concerns about how the Strategic Plan could discriminate against LGBTQ people and women, fail to address the needs of specific underserved populations in accessing healthcare, and restrict access to reproductive health care. We will be monitoring its implementation and working to oppose any such discriminatory HHS policies.

Please contact Vania Leveille at vleveille@aclu.org or 202-715-0806, or Georgeanne Usova at gusova@aclu.org or 202-675-2338 if you have any questions or require additional information.

Sincerely,

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