November 9, 2015

Jocelyn Samuels Director, Office for Civil Rights U.S. Department of Health and Human Services Hubert H. Humphrey Building, Room 509F 200 Independence Avenue SW Washington, DC 20201

Re: 1557 NPRM (RIN 0945-AA02), Nondiscrimination in Health Programs and Activities

Dear Ms. Samuels:

The undersigned national mental health, substance use disorder and children's health organizations are pleased to offer our comments on the proposed rule on Nondiscrimination in Health Programs and Activities. We cannot overstate the importance of this rule because of its potential to ensure that adults and children suffering from mental illness, including substance use disorders, have timely access to needed, high-quality treatment.

Approximately 43.7 million adults have experienced a diagnosable mental disorder in the past year, and 13.6 million live with a serious mental illness such as schizophrenia or bipolar disorder.¹² 21% of all children – 1 in 5 children - have also been diagnosed with a serious mental illness at some point in their lifetime.³ However, only 40% of adults and 50.6% of children ages 8-15 with a diagnosed mental illness – and only 59% of those with a serious mental illness – receive treatment.^{45,6} Despite the huge need, mental health coverage accounts for only 4.8% of all private healthcare expenditures and, excluding prescription drug costs, just 3.1% of all healthcare costs.⁷ This spending is in part kept at artificially low levels because of discriminatory insurance practices that limit access to medically necessary care for patients with mental illness as a disability, which entitles individuals with psychiatric disorders to federal protections.⁸⁹ These protections are expanded to apply to health care services via the Affordable Care Act's Non-Discrimination Provision, Section 1557. Thus the proposed rule on Sec. 1557 holds great promise to help alleviate the discrimination against individuals with mental illness. In order for Sec. 1557's implementation to fully achieve its goals we recommend certain clarifications and additions to strengthen the proposed regulatory text.

We commend HHS on many of the provisions of the proposed rule, and urge their continued inclusion in the final rule:

- *Private Right of Action.* Express recognition of a private right of action for discrimination under Sec. 1557 will be beneficial to patients seeking to enforce their rights.^{10,11} While the internal complaint process at the Office for Civil Rights (OCR) in the Department of Health and Human Services is a helpful option, the increasing number of people with access to health insurance and the demand for mental health services could cause backlogs in OCR which would limit the ability of persons in need of care to have relief in the necessary timeframe. Providing for a private right of action, without the need to first exhaust administrative remedies, is especially important for continuity of enforcement, the achievement of results in a timely manner, and the elimination of discrimination.
- Recognition of Disparate Impact Claims for Discrimination Against Persons with Mental Illness. Discrimination against patients with mental illnesses takes on many forms. Such acts are not always immediately evident and may not always be intentional, but nonetheless disproportionately impact persons with disabilities. For example, a recent study demonstrated that

exchange plan networks of providers were inadequate for certain types of illnesses or disabilities, including mental illnesses.¹² Demonstrating intentional discrimination, absent lengthy discovery, would be very difficult in such circumstances. Accordingly, recognition of disparate impact claims is a significant aid to enforcement.

These aforementioned provisions will help ensure that adults and children with mental illness have consistent and equitable access to care regardless of the type of insurance they have, and substantial options for enforcement of their rights.

However, more can and should be done. The following changes would ensure that the final regulations are consistent with Sec. 1557's intent:

- Explicit Mention in the Regulatory Text That Covered Entity Status of Health Insurance Issuers' Plans Includes Offerings Both In and Outside of the Marketplace. APA fully supports the proposed rule's application of what constitutes a covered health program or activity to include all issuers that receive Federal financial assistance, "whether those issuers' products are offered through the Marketplace, outside the Marketplace, in the individual or group health insurance markets, or as an employee health benefit program through an employer-sponsored group health plan."¹³ We agree that this application is consistent with the existing civil rights principles, including those found in the Rehabilitation Act, its implementing regulations, and case law thereunder.¹⁴ To ensure Sec. 1557's application to all plans of a covered issuer, and to eliminate disputes over this point, we request explicit mention of this in the regulatory text.
- Applying Sec. 1557 Standards to Employee Health Benefit Programs of All Covered Entities. In line with the intended reach of Sec. 1557, the final rule should not exempt certain employee health benefit programs of covered entities. Employee health benefit programs are indisputably health programs and activities, and HHS acknowledges as much by proposing that Sec. 1557 reaches these programs when operated by an entity principally engaged in providing health services or health insurance, when an entity receives federal funding with a primary objective of funding the employee health benefit program, and for those employees of a health program or activity that receives federal funding in an entity not principally engaged in providing health services or health insurance. These are important protections, but there is ultimately no justification for providing more limited protection for discrimination in employee health benefit programs and activities.
- *Covered Entity Third Party Administrator (TPA) Liability*. Footnote 73 of the proposed rule states that when an entity that acts as a TPA for an employer's employee health benefit plan is legally separate from an issuer that receives Federal financial assistance for its insurance plans, HHS will engage in a case-by-case analysis as to whether that entity is subject to Sec. 1557.¹⁵ More clarity regarding this assertion is needed. As currently stated, it could encourage discrimination without potential liability, simply because of a corporate structure. A TPA that administers a discriminatory plan should be liable for discrimination. This is not an unusual concept. For example, if an employer were to hire a search firm and in the description of the position said to exclude all women, minorities, and persons with handicaps, the search firm which followed that direction would be liable for discriminatory manner should be liable for that discriminatory plan or who applies the plan terms in a discriminatory manner should be liable for that discrimination. At the very least, any TPA which exercises total control and discretion over the provision of benefits should be liable for violations of the law.¹⁶
- *Disclosure Obligations to Aggrieved Parties.* The final rule should clarify the types of information to which an aggrieved party is entitled and that a covered entity is obligated to provide. The proposed rule delineates both informal and formal dispute resolution requirements.

Informally, the rule proposes that covered entities adopt grievance procedures and due process standards that "allow for the prompt and equitable resolution of complaints concerning actions prohibited by Section 1557."¹⁷However, the proposed rule is silent on the types of information that the issuer must provide if a consumer chooses to file a grievance based on discrimination or in order to evaluate whether there is a reasonable claim of discrimination in the first instance. A complainant should be entitled to a broad range of plan documents, including internal Sec. 1557 compliance reviews that may be pertinent to their discrimination complaint. While the proposed rule unequivocally clarifies OCR's right to access information, it is unclear what is available to an aggrieved party short of discovery through litigation. Without a defined entitlement to a broad range of plan documents pertinent to the basis for the complaint, the ability to credibly formulate and document a complaint is extremely difficult. Transparency is essential to accountability in this regard. Without such transparency on the part of the covered entity, the credibility and probability of resolution is greatly diminished. Therefore, the final rule should clarify entitlement to essential information on the part of a complainant. Access should be defined to include a broad range of plan documents which may be related to the basis for the discriminatory complaint. Section 104b of ERISA, as interpreted by the Department of Labor, is a solid foundation for OCR guidance.

- *Public Disclosure of Investigation Results and Compliance Plans.* The final rule should include a provision that requires the publication of enforcement actions, including the rationale and results of such actions, as well as the compliance correction plans. Published precedent (even if redacted to eliminate specific names) is essential for educating the health insurance industry on what conduct is and is not acceptable under Sec. 1557. Understanding the rationale for OCR's opinions is helpful to other plans in ensuring that they are compliant and helpful for consumers to understand what conduct is acceptable. Without such precedent, the industry is left only with limited guidance, such as Frequently Asked Questions (FAQs), which, while helpful, are often not sufficiently specific to help companies tailor their behavior in accordance with the law.
- *Providing Examples of Discriminatory Marketing and Plan Designs.* The Affordable Care Act eliminated several adverse selection practices employed by health plans against individuals with mental illness, e.g. barring of pre-existing condition exclusions. Yet plans continue to engage in discriminatory marketing and plan design practices, including, but not limited to: limiting access to medically necessary drugs through prescription tiering, narrowing of provider networks, and insufficient disclosure of plan coverage and benefit management all of which reduce access to care for patients with mental illnesses. These and other practices can represent de facto adverse selection by the plan against certain populations and are some of the key methods of discrimination Sec. 1557 should target for elimination. While we recognize that OCR cannot create an exhaustive list, OCR should include in the Rule these and other examples of discriminatory practice that are precluded.

Thank you again for the opportunity to offer our expertise in the areas of mental health to ensure meaningful implementation of Sec. 1557. Please let the undersigned groups know what we can do to assist you.

AIDS Alliance for Women, Infants, Children, Youth & Families American Association for Geriatric Psychiatry American Psychiatric Association Mental Health America NAADAC, the Association for Addiction Professionals National Alliance on Mental Illness National Association for Children's Behavioral Health National Association of State Mental Health Program Directors National Council for Behavioral Health National Health Law Program National League for Nursing RESULTS: The Power to End Poverty The Psychiatric Rehabilitation Association Treatment Communities of America

 $\underline{http://www.nimh.nih.gov/health/statistics/prevalence/any-disorder-among-children.shtml} \ Accessed \ August \ {\tt 3, 2015}.$

⁵ National Institute of Mental Health. (d) Use of Mental Health Services and Treatment Among Children. Available at:

⁶ National Alliance on Mental Illness. Mental Illness FACTS AND NUMBERS. Available at: <u>http://www2.nami.org/factsheets/mentalillness_factsheet.pdf</u>. Accessed August 3, 2015.

⁸ 29 U.S.C. 705(9)(B)

¹³ Proposed Rule at 54189

¹⁷ Proposed Rule at 54178

¹ National Institute of Mental Health. Any Mental Illness Among Adults. Available at: www.nimh.nih.gov/health/statistics/prevalence/anymental-illness-ami-among-adults.shtml. Accessed June 9, 2015.

² National Institute of Mental Health. *Serious Mental Illness Among Adults*. Available at: <u>https://www.nami.org/Learn-More/Mental-Health-By-the-Numbers</u>. Accessed at June 9, 2015/

³ National Institute of Mental Health. (a) Any Disorder Among Children. (n.d.) Available at:

⁴ National Institute of Mental Health. (e) Use of Mental Health Services and Treatment Among Adults. (n.d.) Available at:

http://www.nimh.nih.gov/health/statistics/prevalence/use-of-mental-health-services-and-treatment-among-adults.shtml. Accessed August 3, 2015; National Alliance on Mental Illness. Mental Illness Facts and Numbers.

http://www.nimh.nih.gov/health/statistics/prevalence/use-of-mental-health-services-and-treatment-among-children.shtml. Accessed August 3, 2015.

⁷ Substance Abuse and Mental Health Services Administration. National Expenditures for Mental Health Services and Substance Abuse Treatment, 1986–2009. HHS Publication No. SMA-13-4740. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2013. Available at: <u>https://store.samhsa.gov/shin/content/SMA13-4740/SMA13-4740.pdf</u>. Accessed August 3, 2015.

⁹ 42 U.S.C. 12102

¹⁰ Alexander v. Choate, 469 U.S. 287 (1985)

¹¹ Sarah G. Steege, *Finding a Cure in the Courts: A Private Right of Action for Disparate Impact in Health Care*, 16 Mich. J. Race & L. 439 (2011). Available at: http://repository.law.umich.edu/mirl/vola6/iss2/3

¹² Dorner SC, Jacobs DB, Sommers BD. Adequacy of Outpatient Specialty Care Access in Marketplace Plans Under the Affordable Care Act. JAMA. 2015;314(16):1749-1750. doi:10.1001/jama.2015.9375.

¹⁴ 41 CFR 60-741.1

¹⁵ Proposed Rule at 54189, n. 73

¹⁶ New York State Psychiatric Assn. v. UnitedHealth Group., 798 F. 3d 125, 132-133 (2nd Cir. 2015).