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November 6, 2015

The Honorable Sylvia Burwell
Secretary
Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

Re: Comments on the Nondiscrimination in Health Programs and Activities
Notice of Proposed Rulemaking

Dear Secretary Burwell:

Thank you for the opportunity to comment on the proposed Nondiscrimination in Health Programs and Activities rule released September 8, 2015. **While we support the added protections for certain individuals, we feel that this rule missed an opportunity to increase protections for people with chronic diseases and disabilities by working to eliminate discriminatory plan design.**

The National Health Council (NHC) is the only organization that brings together all segments of the health community to provide a united voice for the more than 133 million people with chronic diseases and disabilities and their family caregivers. Made up of more than 100 national health-related organizations and businesses, its core membership includes the nation's leading patient advocacy groups, which control its governance. Other members include professional societies and membership associations, nonprofit organizations with an interest in health, and major pharmaceutical, medical device, biotechnology, and health insurance companies.

We are encouraged that the Affordable Care Act (ACA) has added and expanded upon important patient protections as more Americans gain access to health insurance coverage. The Department of Health and Human Services' (HHS) clarifications around discriminatory behavior in the market are critically important to ensuring that vulnerable patients are not taken advantage of or excluded from coverage through what have become common discriminatory practices. HHS's continued oversight will be vital to guaranteeing that the ACA meaningfully improves access to comprehensive health care coverage. Moving forward we hope that HHS will not only continue its oversight, but expand oversight to monitor benefit design more closely.

The NHC Applauds HHS's Clarification on Prohibited Discriminatory Activity and New Standards on the Grievance Process

The standards prohibiting discrimination based on disability, gender, and language, which are included in the proposed rule, provide additional clarity around what qualifies as discriminatory behavior. NHC is pleased the language proposed by HHS would guarantee meaningful access for individuals with limited English proficiency, effective communication for individuals with disabilities, and equal program access on the basis of sex. While these provisions are not new in practice, HHS's interpretation of discriminatory behavior will improve access for individuals who in the past have been marginalized. We hope that HHS will finalize these proposals, as they appear to be a straightforward baseline for defining discrimination for many individuals.

The NHC also supports the proposal to adopt due process in grievance procedures and a process for educating enrollees about the grievance process itself. An appeals process can only benefit enrollees who understand their rights. We agree that equitable resolutions must be found promptly to avoid unnecessary gaps in coverage. Therefore, we urge HHS to finalize its updates to the process and continue to evolve the appeals and grievance to best meet the needs of all individuals and families enrolled in health plans nationwide.

HHS Must Provide Clear Guidance and Oversight of What Qualifies As Discriminatory Benefit Design

While we agree that the appeals process is one tool to uncover discriminatory plan design, we do not believe that it is wholly sufficient. Even with attempts to educate patients about their rights, it will be very difficult to ensure that every patient knows about the process, and many individuals will still choose not to appeal. Additionally, for many patients, there will still likely be a gap in access which may have a very detrimental impact on their health. Therefore, we urge HHS to strengthen the plan review process to proactively discover discriminatory plans and prevent them from reaching the market.

As a united voice for people with chronic diseases and disabilities, the NHC believes that broad patient protections are critical to the success of the ACA. HHS must take a stronger position to enforce regulations around what qualifies as discriminatory benefit design. As guaranteed issue and rating rules have extended access to health insurance to those with diagnosed conditions, we are concerned that some plans now manage risk through inappropriately taking advantage of the flexibility allowed on benefit design. Fundamental provisions in the ACA envisioned a level playing field for individuals with chronic conditions. The law was written to protect people who, in the past, may not have had access to comprehensive health care. Some plans, it seems, push the limits in benefit design, hurting the most vulnerable people who require care on a regular basis.

Adverse formulary tiering, delays in access to new medications, broad use of utilization management within a particular drug category or class, and limited provider networks (particularly for specialists) can have the effect of limiting access to care for people with chronic conditions. We believe that some plans are making it difficult for individuals to manage their conditions, which leaves patients with complex health needs few options for appropriate coverage.

Examples of discriminatory benefit design have been covered by the mainstream media. The AIDS Institute brought to light discriminatory benefit design in both Florida and Illinois for HIV/AIDS medications. Their latest efforts now focus on similar concerns regarding access to hepatitis care. This particular issue first arose last year when consumers filed lawsuits against their insurers for strict medical necessity criteria. However, these practices have not been limited to the HIV/AIDS community. Transplant recipients, individuals with mental illness, and others have also seen drug formulary designs that place all medications, including generics, on the highest cost sharing tiers. In addition, discriminatory benefit designs are not limited to drug formularies. Poor network adequacy for specialty care, provider tiering, and other practices have singled out people with chronic conditions and shifted a greater cost of care to these individuals, impeding their access to care.

Discriminatory benefit design was addressed in the 2016 Notice of Benefits and Payment Parameters, though we believe that the requirements issued by HHS in that rule fell short of offering clarification on the concept of discriminatory benefit design. In fact, the majority of the guidance on discriminatory benefit design was in the rule's preamble, not in the regulatory text.

The proposed rule on Nondiscrimination in Health Programs and Activities is a long-awaited opportunity to address the concerns of the patient community regarding discriminatory benefit design. Though this rule introduces important protections for specific subsets of people, it does not address the fact that flexibility afforded to plans in designing benefits leaves room for patients to fall through the cracks. As patients with disabilities are protected under the Americans with Disabilities Amendments Act, we believe these protections should be extended to people with chronic medical conditions, who should be protected from discriminatory insurance benefit designs.

We urge HHS to expand the rule to consider any insurance plan that limits access to care for individuals with a diagnosed condition to be discriminatory and be prohibited from the insurance market.

The proposed rule marks an encouraging shift in HHS oversight of health plan practices. This rule should go further to guarantee that the nation's most vulnerable patients have access to appropriate health coverage. It is not only the fair solution, but it also will improve health outcomes and potentially lower overall expenditures. Effective disease management cannot be considered a possibility without suitable protections for these patients, guaranteeing necessary health care coverage.

Please do not hesitate to contact Eric Gascho, our Assistant Vice President of Government Affairs, if you or your staff would like to discuss these issues in greater detail. He is reachable by phone at 202-973-0545 or via e-mail at egascho@nhcouncil.org.

Sincerely,



Marc Boutin, JD
Chief Executive Officer