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Oct. 3, 2022

Melanie Fontes Rainer
Acting Director
Office for Civil Rights
Department of Health and Human Services
200 Independence Avenue, SW
Room 509F, HHH Building
Washington, D.C. 20201

Re: 1557 NPRM (RIN 0945-AA17)

Submitted via www.regulations.gov

Dear Acting Director Fontes Rainer,

On behalf of over 220 children's hospitals across the country, the Children's Hospital Association (CHA) appreciates the opportunity to provide comments on the Centers for Medicare & Medicaid Services (CMS) and Office for Civil Rights (OCR) proposed rule, "Nondiscrimination in Health Programs and Activities". We strongly support the proposed rule, which restores critically important civil rights protections under Section 1557 of the ACA for key children's health programs and activities administered and/or funded by HHS, as well as commercial health insurance plans. The restoration of these protections has significant implications on access to comprehensive child and family-centered health care services and programs that are affordable, timely and appropriate for all children and adolescents regardless of their race, color, national origin, gender, gender identity, age or disability.

Children's hospitals are a vital safety net for all children. Although they account for only 3% of hospitals in the United States, children's hospitals care for almost one-half of children admitted to hospitals, the majority of children with serious, complex and/or chronic conditions and most children in need of major surgical services. Children's hospitals serve as a vital safety net for uninsured, underinsured and publicly insured children and are regional centers for children's health, providing care across large geographic areas.

It is critically important that all children and adolescents have access to culturally appropriate and equitable health services, programs and coverage to ensure their physical and mental health. Since children are still developing, they are particularly vulnerable to harm when they lack access to timely pediatric physical and mental health care and can suffer life-long physical and mental health consequences that generate extensive and avoidable possible long-term health care impacts and unnecessary costs. There are many ways that children can end up with substandard care as a result of health plans, programs and systems that are not designed to meet their unique needs.

Our comments highlight specific aspects of the proposed rule that are particularly important for our pediatric population, including:

- The affirmation that Section 1557 applies to all HHS-funded and administered programs, including Medicaid and CHIP, as intended by the ACA.

- The delineation of protections and requirements that will help ensure equitable access to high-quality, appropriate health care services and programs that are culturally and linguistically appropriate for children and families with limited English proficiency (LEP) and meet the needs of LGBTQ+ youth.

- The application of 1557 protections to private health insurance plan (including short-term limited duration plans) practices, such as provider network design, covered benefits, marketing, drug formularies, visit limits and utilization management.

Our comments also include recommendations where we believe the rule can be strengthened to better meet the unique health care needs of children and youth, including:

- Clarifying that Section 1557 compliant health plan benefit designs must include a robust set of medically necessary pediatric services, without arbitrary limits to meet children's unique and changing developmental needs.

- Specifying that exclusion of specialty providers, such as children's hospitals, from a provider network, or the tiering of those providers into higher-cost tiers violates Section 1557 age and health status nondiscrimination standards.

- Requiring compliance with the Mental Health Parity and Addiction Equity Act (MHPAEA) in order to be considered in compliance with Section 1557.

- Addressing the ways that pediatric care differs from adult care in determinations of whether a covered entity's use of telehealth is discriminatory.

Our detailed comments are below.

Applicability to federal health programs (§ 92.2)

We support the proposed rule's recognition that Section 1557 applies to all federal health programs, including Medicaid, CHIP, the Marketplace and qualified health plans that receive federal financial assistance. We also are pleased that the rule reinstates Section 1557 applicability to commercial health plans, including short-term limited duration plans.

Notice of availability of language assistance services and auxiliary aids and services (§ 92.11)

We generally support the modifications to the proposed rule on taglines that now require covered entities to provide an annual notice—through written translations, recorded audio or video clips—that states, at a minimum, that the entity provides language assistance services and appropriate auxiliary aids and services free of charge. We also agree that those notices should be provided in the languages most commonly spoken by LEP individuals.

However, we respectfully note that the top 15 languages spoken by LEP individuals who are served by a particular provider may not be the same as the top 15 languages spoken across that provider's state or states. For example, a hospital located in a large diverse urban area within a more rural state may see patients for whom the top languages are very different than those in the state itself. Therefore, we encourage HHS to require taglines to be in the top 15 languages within a provider's or entity's own service/catchment area rather than within the state or states as a whole. This or an alternative targeted approach will help ensure that the taglines actually meet the needs of those served by the entity. We also suggest that OCR develop and provide covered entities with model notices and translated information that they can then adapt to meet their own needs. The availability of model notices and translations will help facilitate compliance as well as uniformity across entities in terms of the information that is provided.

Meaningful access for individuals with limited English proficiency (LEP) (§ 92.201)
We support the proposed rule's requirement that covered entities take reasonable steps to assess and provide meaningful and timely access to programs or activities by individuals with LEP, including a parent seeking health services for a child. Children's hospitals provide competent and high-value language support to families through phone, video and in-person interpretation. For example, it is not uncommon for hospitals to track preferred language of the caregiver in the electronic health record, identify the need for language support prior to a patient's visit and incorporate the scheduling of an interpreter into the clinical scheduling process. Hospitals also plan for, schedule and provide individuals to read for families, provide large-print if needed and in-person interpreters, if possible, for families in need of sign language.

We also agree that qualified translators should be required to review machine translation when the information provided is highly complex. Translation is not something that can be done well or quickly by a machine in a clinical setting. It is also very difficult to do machine translation in multiple languages to meet the needs of the diverse populations with LEP who children's hospitals serve. Quality translation requires human interaction and is essential in health care and it is imperative that machine translation not create confusion or medical error.

Finally, we strongly support the provision to allow states to claim Medicaid reimbursement for the cost of interpretation services, either as medical assistance or administration-related expenditures. The provision of these services is costly to health care organizations and should be financially supported.

Equal program access on the basis of sex (§ 92.206)
We support the proposed rule's reinstatement of key requirements that health services, programs and plans provide equitable access and coverage regardless of race, color, national origin, gender, gender identity, age or disability. This proposed rule, if finalized, importantly reduces the potential for discrimination against some of the more vulnerable children, adolescents and families that we serve, including LGBTQ+ youth.

In particular, we support the rule's affirmation that Section 1557 protects individuals seeking gender-affirming care from discrimination and agree that this care, like all medical services, should follow clinical practice guidelines and professional standards of care, including standards for informed consent. Children need access to health care delivered by specialty trained clinicians in safe, supportive and inclusive environments. Research shows gender-affirming care improves the health and overall well-being of children and youth when families and medical professionals work together in making health care decisions. The proposed rule prohibits actions that could limit the availability of health care services or deter children and adolescents from seeking timely and appropriate care. Increased gaps in the availability of high-quality, culturally competent care due to discrimination, especially in localities where access issues already exist, could have serious implications for long-term physical and mental health and well-being.

To better help ensure that all children and youth, including gender nonconforming and transgender youth, have access to the care they need, we suggest that "transgender" be enumerated specifically in the rule, in addition to "gender identity." This clarification will help further protect against targeted discrimination against transgender youth. We also suggest that the rule specify that Section 1557, as federal law, preempts state or local laws that may restrict care and services.

Nondiscrimination in health insurance coverage and other health-related coverage (§ 92.207)
We are pleased that the proposed rule recognizes and prohibits specific private insurance practices that lead to inadequate coverage and access to care, and we support strong regulatory protections prohibiting discriminatory plan benefit design and marketing practices. At the same time, we note that there are additional steps HHS can take to ensure that insurer practices are not discriminating against children, particularly children with chronic or complex medical conditions.

Children are not little adults and require comprehensive, pediatric-specific health benefits and provider networks to address their unique needs. Plans that do not ensure children have access to all medically necessary benefits without arbitrary limits and access to in-network providers with pediatric training and expertise should be considered discriminatory under Section 1557 based on age and health status. The failure of a plan to appropriately meet a child's needs is not only detrimental to a child's well-being, but also creates life-long health consequences that generate extensive and avoidable costs.

We recommend that the final rule include provisions specifically designed to protect children and youth from potentially discriminatory health plan practices. These include:

- Age-appropriate benefit packages – Plans should be required to demonstrate that their pediatric benefit package is comprehensive and age-appropriate, similar to Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit and CHIP's benefit packages. Both EPSDT and CHIP have robust benefits that give children access to the full range of medically necessary preventive, diagnostic and treatment services needed for their healthy growth and development. Issuers should also be required to demonstrate that these physical and mental health benefits do not have arbitrary age, visit or coverage limits that are not based on medical necessity or are based on adult metrics.

  Children need more frequent preventive and supportive services than adults, including immunizations, developmental assessments and screenings and nutritional counseling, to enable them to maintain or improve their physical and mental health well into adulthood. Furthermore, a child with special health care needs may need additional services on a more frequent basis than an adult to enable them to develop specific skills or meet their developmental potential, such as speech or physical therapy. That child will also require replacement of durable medical equipment or devices (such as a wheelchair) on a much more frequent schedule than is provided in an adult benefit package—a new wheelchair every five years may be adequate for an adult, but not for a child. Plans that limit coverage, without a medical basis, to a certain number of visits, specific condition or child's capacity to attain a certain functional status will unfairly prevent many children with special health care needs from accessing critically important services.

- Pediatric-specific provider networks – We agree with the proposed rule's statement that narrow networks can be discriminatory and urge HHS to specify that any network design that restricts access to specialty providers, such as children's hospitals, or imposes financial barriers that impede access to those providers are discriminatory under Section 1557. For example, a network that does not include specialty providers with the appropriate pediatric clinical expertise and training to care for children with chronic or complex conditions will not only be insufficient for those children but could result in unanticipated costs for children and their families when they are forced to seek out-of-network care. Furthermore, narrow or tiered networks may impose administrative burdens on enrolled children and families, which may delay or otherwise impede access or deter families of children with serious medical needs from enrolling in a given plan or product at all.

- Access to mental health services and providers – Oversight and implementation of mental health parity protections is essential to upholding nondiscrimination standards. The final rule should specify that nondiscriminatory benefit designs must reflect proper implementation of mental health parity protections, including those related to non-quantitative treatment limitations, which may otherwise serve as barriers to children's access to clinically appropriate mental and behavioral health services. We ask HHS to clarify that nondiscriminatory benefit designs must encompass the full range of services critical to children with mental and behavioral health needs, including intermediate-level services offered by many children's hospitals and other community providers targeted at children who are high-utilizers of mental and behavioral health care.

The Department of Labor and HHS's joint 2022 annual report on private health plan compliance with the Mental Health Parity and Addiction Equity Act (MHPAEA)[1] clearly shows that health plans miss the mark on parity. For the 43% of the nation's children who have private insurance coverage through employer-sponsored or Marketplace plans, the violations cited in the report mean needless delays. To comply with Section 1557, health plans must achieve true mental health parity to help ensure that children have access to the full spectrum of providers capable of delivering the mental and behavioral health care they need, including but not limited to pediatric mental/behavioral health specialists, primary care physicians, licensed clinical social workers and nurse practitioners.

Furthermore, to fully meet Section 1557 requirements, payers (both public and private) must remedy the current inadequacies and inequities in mental health services reimbursement rates and policies. Rates of reimbursement have historically been lower for mental health services, which contributes to difficulty in both recruitment and retention into mental health fields, leading to significant barriers to care for children. We encourage OCR to include an examination of payment policies in its oversight of 1557 compliance.

Nondiscrimination in the delivery of health programs and activities through telehealth services (§ 92.211)
We support the prohibition on discrimination in the provision of telehealth services. Telehealth played a major role in the care of all children during the COVID-19 pandemic and continues to do so, particularly for children with special health care needs. The proposed rule's application to telehealth is an important step to ensuring that these services continue to be accessible to all who need them.

There are certain aspects of pediatric care that differ from adult care that should be considered when determining whether a covered entity's use of telehealth is discriminatory. For example, telehealth services that are appropriate for adults may not be appropriate for children or adolescents without the presence of a parent, such as when the child cannot verbally communicate with the clinician. Additionally, there are different privacy, informed consent and security issues associated with pediatric telehealth, particularly for telehealth in school-based settings.

In addition, we believe that inadequate and inequitable reimbursement policies for telehealth services across payers should be considered discriminatory under Section 1557. Reimbursement is a primary driver of telehealth adoption by providers and consistent reimbursement policy across payers is important to encourage providers to furnish telehealth services. Currently, there is inconsistency in the types of telehealth services and providers that are eligible for reimbursement. There are also inconsistencies in payment for telehealth services—either telehealth services being paid at a different rate than in-person services or states not requiring payment parity in private health plans for telehealth and in-person services.

We also encourage OCR to consider telehealth coverage policies, including medical management requirements that limit access, as discriminatory under 1557. For example, while private payers currently waive prior authorization for telehealth services as part of their COVID-19 response, they are not tied to any timeframe, which presents an additional layer of variation in coverage and reimbursement.

In addition, we note that there are opportunities for national Medicaid policies that could address current inequities (and possibly discriminatory differences) in access to telehealth services across the country for children, either through existing authority or statutory changes. This is particularly important for children with special health care needs or complex conditions who routinely need to connect with providers not in their states. How telehealth policies translate across state lines is critical for children to be able to access needed care, especially children with special needs or complex conditions, such as those who are dependent on technology.

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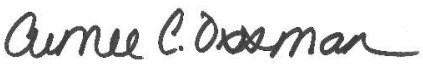
[1] See 2022 MHPAEA Report to Congress (dol.gov). April 2022.

Finally, we seek further clarification related to the requirement that the covered entity provide meaningful access to telehealth services for LEP individuals and individuals with disabilities. Specifically, is the covered entity obligated to provide needed equipment to those individuals who do not have it to allow full participation in telehealth services?

Enforcement mechanisms (§ 92.301)
We are pleased that the rule reinstates key enforcement mechanisms and support clear, accessible procedures for filing, investigating and remediating discrimination complaints, including the reestablishment of the Right of Private Action in federal court. The reinstatement of these grievance procedures and rights gives families needed recourse in the event they face discriminatory limits on access to comprehensive, medically necessary quality care.

We appreciate the opportunity to provide comments on the proposed regulation. Children's hospitals look forward to working with HHS to implement the Section 1557 nondiscrimination protections to ensure that children have timely access to the services they need. If you have any questions about our comments, please contact Jan Kaplan at 202-753-5384 or jan.kaplan@childrenshospitals.org.

Thank you,



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