

September 30, 2013

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

**Re: 1557 RFI (RIN 0945-AA02), Request for Information**

To Whom It May Concern:

As organizations that share a strong commitment to the health of our nation's children, we appreciate the opportunity to share recommendations with you regarding the HHS Request for Information (RFI) noted above. This RFI will lay the groundwork for further implementation of sec. 1557 of the Affordable Care Act, which prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in certain health programs and activities.

Pursuant to the RFI, we have responded to the specific questions it poses. Our collective response focuses on discrimination based on age, disability (including mental health conditions), sex, and national origin.

**Question 3: What are the impacts of discrimination?**

The RFI seeks information on the possible consequences of unequal access to health programs and services, such as delays in diagnosis or treatment, or receipt of an incorrect diagnosis or treatment.

While there is seldom intentional discrimination against children, there are many ways that children can end up with substandard care because many health insurance plans and health care delivery systems have been developed without consideration of their needs. And, since children are still developing, they are particularly vulnerable to harm when they lack access to timely and appropriate pediatric health care. Children can face severe, even life-threatening, consequences when they do not have access to the appropriate pediatric providers to diagnose and treat them. Children are not just little adults. They are developing physically, mentally and emotionally and their bodies react differently than those of adults. Children require extra time, monitoring, specialized medications and specially trained health care providers. Therefore, they must have access to health care that is focused on their unique needs and is family-centered.

Healthy young children need immunizations and other well-child care to stay healthy and to detect any developmental difficulties. Children with developmental delays, disabilities or chronic or serious health conditions need early diagnosis and treatment to increase their chances of ameliorating their conditions. Early intervention is critical in maximizing children's potential to function, whether their condition is physical, cognitive or emotional. In some cases, early

intervention can prevent a child from needing special education once he or she enters school or lengthy medical treatment.

With respect to medications, children react differently than adults. They may need a different formulation of a medication (e.g., liquid instead of pills), or may need a brand-name medication rather than a generic form of the same drug. Because many drugs have not been tested on children, their physicians may need to prescribe drugs for off-label use.

As with medication, children may need certain therapies that have not yet undergone clinical trials, allowing insurers to claim that the treatments are “experimental,” and thus deny coverage.

Additionally, children with developmental disabilities or delays may need therapies – e.g., occupational, speech and physical therapy -- more frequently or for a longer period of time than adults because they may be acquiring skills for the first time, rather than reacquiring them as adults would after an injury or stroke, for example. Children also need certain medical equipment and devices (e.g., wheelchairs, eyeglasses, prosthetic limbs) more frequently than adults do, simply because they are growing.

Further, children’s physical and cognitive development must be taken into account when they are being treated. Thus, it is vital that children have access to providers trained in pediatrics, such as pediatric subspecialists in cardiology, neurology and oncology, which are just some examples of specialties in which pediatric conditions, and their treatments, are significantly different from those of adults.

When emergencies arise, it is critical that health care facilities be equipped to handle children; they need to have child-sized face masks, blood pressure cuffs, and other equipment, as well as personnel trained to treat children in emergent situations.

In short, all children face age discrimination -- barriers to appropriate health care based on the simple fact that they are children. Some children also face potential inequities in care due to disability, diagnosis (e.g., mental health or substance abuse conditions), or national origin.

Fortunately, these disparities in the treatment of children can be addressed through Sec. 1557 in the following ways.

**Health plans must adequately cover all the benefits that children need.**

With respect to essential health benefits (EHB), maternal and child health advocates have provided HHS with previous communications regarding other non-discrimination requirements of the ACA.<sup>[1]</sup> We respectfully request that HHS re-examine its decision to effectively cede authority for the determination of what constitutes EHB to states. We believe that the

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<sup>[1]</sup> See §1302(b)(4)(B). “the Secretary shall...(B) not make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of their age, disability, or expected length of life.” Sec. 1557 bolsters this requirement as sec. 1557 applies to Title I of the ACA.

Secretary's current decision to grant states the authority to select EHBs may violate both sec. 1302(b)(4)(B) and sec. 1557 of the ACA and urge its reconsideration.

We have a special concern about potential discrimination against children with disabilities with respect to the coverage of "habilitation" benefits. We believe that, to fully comply with non-discrimination requirements, the EHB packages in every state must cover habilitation services and devices as separate and distinct from rehabilitation. For example, the plan cannot substitute rehabilitation for habilitation or apply arbitrary caps on services that are not based on medical necessity. Nor can plans be allowed to institute copayments or quantitative treatment limits that are not applied to other benefit categories.

### **Qualified Health Plans must ensure network adequacy.**

Pediatric and obstetric and gynecological provider network standards for QHPs should specifically reflect the challenges faced by especially vulnerable populations, such as children with special health care needs and women with high-risk pregnancies, including those with complex conditions or limited English proficiency, in securing the care they need when they need it.

Network adequacy standards must require an appropriate distribution of pediatric specialists. Limited or tiered networks that create barriers to appropriate care or substantial disruptions of care and provider relationships can be catastrophic to the development and health of children with special health care needs and women with high-risk pregnancies.

Children and pregnant women must be able to access the specialty care they need even when the QHP network has an insufficient number or type of provider to provide the needed care. Children and pregnant women with complex or chronic conditions may need specialty care from a type of provider not in a QHP network, given the shortage of certain types of pediatric specialists nationwide and the possibility of narrow provider networks in some plans. Therefore, children must be able to access those providers at no additional cost and do so in a timely manner when it is determined that the care is appropriate.

Further, QHP policies and rules for accessing out-of-network care and the process for appeals of denials of requests for out-of-network care must be made clear to consumers.

Additionally, provider networks must include providers who offer services in the appropriate languages to serve the population. Children's health could suffer if parents are unable to find linguistically and culturally appropriate providers for their families.

### **Families must have access to the information they need to make appropriate coverage decisions for their children.**

Because children's health care and coverage needs differ significantly from those of adults, consumer assistance personnel (Navigators, in-person assisters, and certified application counselors) must be trained to:

- Understand and explain the differences in health plans and provider networks and how these differences impact children;
- Have a thorough knowledge of the unique role of Medicaid and the Children’s Health Insurance Program (CHIP) for children and pregnant women’s coverage, including the different eligibility pathways for various pediatric populations and for low-income pregnant women who may be eligible for both Medicaid and the Marketplace.
- Understand the service needs of children with complex and chronic conditions and applicable coverage and provider network differences in the qualified health plans offered in the Exchange (or contact organizations in their state with relevant expertise, such as the Family-to-Family Health Information Centers).

**Mental health and substance abuse treatment must be on par with treatment for other conditions.**

Since the tragic events in Newtown, CT, there has been a renewed focus on the mental health system in the U.S. and discussion of whether that system is meeting the needs of our nation’s children. For too long, children with mental health and substance use disorders have faced discrimination in access to services and costs associated with those services compared with medical care. Treating conditions related to the brain as different from those of the body is a form of discrimination and is particularly problematic for children since many chronic mental health conditions manifest themselves in adolescence. Therefore, screening and early intervention in children is critical. Mental health carve-outs in public and private insurance are a significant barrier to access to mental health care for many children, and thereby function as a form of discrimination against children with mental health conditions.

The Administration has taken significant strides in relation to mental health and we look forward to the issuance of final rules implementing the Mental Health Parity and Addiction Equity Act. We remain concerned, however, with respect to the coverage of mental health and substance use disorder services in qualified health plans and how mental health parity will be assessed and enforced in qualified health plans. As HHS considers implementation of sec. 1557, we would encourage the Department to give special consideration to the discrimination faced by children with mental health conditions in federal programs and public and private insurance plans.

**Question 5: Sex discrimination -- maternity care.**

Some health insurance plans fail to cover pregnancy-related services for dependents and others. This is especially concerning, given the law’s provisions permitting dependents to remain on a parent’s plan until age 26. We believe that Section 1557’s prohibition of sex discrimination necessarily includes discrimination based on pregnancy, as the RFI rightly notes.<sup>1</sup> Pregnancy

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<sup>1</sup> Dep’t of Health & Human Servs., Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities, 78 Fed. Reg. 46,558, 46,559 (proposed Aug. 1, 2013).

discrimination constitutes sex discrimination under Title IX<sup>2</sup> and other civil rights statutes such as Title VII<sup>3</sup> and thus also constitutes sex discrimination under Section 1557. These laws prohibit discrimination based on pregnancy itself, as well as pregnancy-related conditions.<sup>4</sup> Section 1557 regulations should expressly recognize this basic principle and ban plans from excluding maternity care, including maternity care for dependents, from their coverage.

**Question 8: Other issues important to the implementation of Section 1557 that should be considered.**

Children with disabilities and other special health care needs often have difficulty getting the care they need and/or getting that care paid for by their insurers. ACA contains several private insurance reforms that should help children with disabilities and other special health care needs, including the prohibition on denying or charging more for insurance coverage based on pre-existing conditions, and the ban on lifetime and annual benefit caps. Nonetheless, more can be done to ensure continued positive outcomes for these children by increasing their access to care that is coordinated and integrated, such as the care provided through medical homes.

Children with disabilities cared for in medical homes, which provide care coordination, benefit from increased access to subspecialty care, fewer missed days of school, and decreased family financial burden. Moreover, having a medical home is a predictor for less inpatient and emergency department utilization and fewer unmet medical and support service needs. Despite these benefits, only half of all children with special health care needs currently receive care consistent with an ideal medical home, a proportion that is significantly lower than that of their typically developing peers. Currently, living in poverty or certain geographic locations and having a more severe disability or certain conditions, such as autism, further limit a child's access to a medical home. As HHS considers State Plan Amendments submitted under the Medicaid Health Home State Plan Option, special attention should be given to whether or not these plans address barriers to access for children with disabilities.

We also encourage HHS to look closely at the policies that directly or indirectly prevent children and pregnant women who are immigrants or who come from mixed-status families, from accessing health care services. Barring immigrant children and pregnant women from Medicaid and CHIP, which nearly half of all states still do, remains a harmful, discriminatory barrier to health care access. As HHS moves forward on implementing Sec. 1557, we encourage the Department to ensure that eligible individuals, including those living in immigrant families, have an equal opportunity to secure the services made available under the ACA, without regard to their race, ethnicity or national origin.

Thank you for your attention to the views of maternal and child health advocates.

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<sup>2</sup> 34 C.F.R. § 106.40(b)(1) (2012). See also *Pfeiffer v. Marion Ctr. Area Sch. Dist.*, 917 F.2d 779, 784 (3d Cir. 1990); *Hogan v. Ogden*, No. CV-06-5078-EFS, 2008 U.S. Dist. LEXIS 58359, at \*26 (E.D. Wash. July 30, 2008); *Chipman v. Grant County Sch. Dist.*, 30 F. Supp. 2d 975, 977-78 (E.D. Ky. 1998); *Hall v. Lee Coll.*, 932 F. Supp. 1027, 1033 n.1 (E.D. Tenn. 1996); *Cazares v. Barber*, Case No. CIV-90-0128-TUC-ACM, slip op. (D. Ariz. May 31, 1990); *Wort v. Vierling*, Case No. 82-3169, slip op. (C.D. Ill. Sept. 4, 1984), *aff'd*, 778 F.2d 1233 (7th Cir. 1985).

<sup>3</sup> 42 U.S.C. § 2000e(k) (2012). See also 29 C.F.R. pt. 1604 app.; *Newport News Shipbuilding & Dry Dock v. EEOC*, 462 U.S. 669 (1983).

<sup>4</sup> See, e.g., 42 USC § 2000e(k) (2012).

Sincerely,

American Academy of Pediatrics  
Children's Defense Fund  
Children's Hospital Association  
Family Voices  
First Focus  
Georgetown University Center for Children and Families  
March of Dimes