January 27, 2022

Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-9911-P.
P.O. Box 8016
Baltimore, MD 21244-8016
[Submitted electronically]

Dear Administrator Brooks-LaSure,

As organizations that share a strong commitment to the health of our nation's children, we appreciate the opportunity to provide comments in response to the proposed rule, "Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2023" (proposed rule). Our organizations believe that all coverage for children must ensure access to timely, affordable, high-quality, and age-appropriate health care (including mental health, dental, vision, and hearing services) that meets their unique developmental needs and enables them to meet their full potential as adults. It must also promote the health of women before, during and between pregnancies. Access to health care for children and their families is vital to long-term health, well-being, and productivity.

Our comments below highlight our general support for key policy changes that are included in the proposed rule and have positive implications for children's health and health care. We also provide you with our recommendations for additional actions that we believe are necessary to ensure that private coverage options for children—particularly children with serious, chronic and complex conditions—meet their unique needs. In particular, we urge you to take action in future rulemaking to:

- Strengthen the pediatric services category of the EHBs to include all age-appropriate preventive, diagnostic and treatment services that are medically necessary for children, including those who have a chronic condition, functional impairment, or significant or multiple health risks.
- Design a pediatric-appropriate federal network adequacy framework that uses a set of multi-faceted metrics to take into account the full range of children's physical and mental health and developmental needs—including children who have serious, chronic or complex conditions—geographic challenges, and the regionalization of pediatric specialty care.
- Clarify that deductible exemptions in standardized plans apply to the full range of pediatric preventive services and apply the deductible exemption and cost-sharing limits to habilitative services.
- Rescind the final rules that extended the availability of non ACA-compliant plans, including short-term limited duration insurance plans, association health plans and health care sharing ministries.

Our detailed comments are below.

Guaranteed Availability of Coverage (§ 147.104)

We support the proposed reinterpretation of the current guaranteed availability rules with respect to non-payment of premium to prohibit issuers from refusing to effectuate new coverage due to failure to pay outstanding premium debts from the previous year. The current policy creates barriers to coverage for low-

income children and families and is inconsistent with the ACA's provision on guaranteed issue. Children and pregnant women must be able to get the care they need when they need it without jeopardizing their families' financial security. Therefore, we support the inclusion of this provision in the final rule.

Standardized Options (§155.20)

We are pleased that CMS will be resuming the designation of standardized options and proposing plan designs in the 2023 Notice. This policy change will make it easier for families to compare plan offerings and choose health insurance plans that fit their needs. We respectfully provide the following recommendations on ways the options can best meet the needs of children, particularly children with serious, chronic, or complex health concerns:

- Clarify that deductible exemptions apply to the full range of pediatric preventive services, including those provided by a pediatric specialist. Children with chronic or complex medical conditions visit their medical specialists more frequently and may rely on them for their well-child and other preventive screenings, including immunizations.
- Apply the deductible exemption and cost-sharing limits to habilitative services. Coverage of habilitative services and devices is a critically important benefit for children who may suffer from a condition at birth (such as cerebral palsy, autism or spina bifida) or from an illness or injury that prevents normal skills development and functioning. Standardized cost-sharing structures for these services should be incorporated into the options to both inform consumer plan choice and convey the potential financial impact of using these important therapies.
- Delineate the specific types of adult and pediatric specialist visits that are exempt from the deductible and if there are any limits on the number of visits that are allowed under the exemption.
- Require the use of copayments, rather than coinsurance for specialty visits and specialty drugs in all the options. Coinsurance is a confusing concept for many consumers that does not allow them to accurately determine their costs of care and can result in a higher financial burden.

Non-Interference With Federal Law and Non-Discrimination Standards (§ 155.120(C))

We applaud the agency for including a proposal to amend § 155.120(C) to explicitly prohibit discriminatory actions by an Exchange that are based on sexual orientation and gender identity.

Despite some advances in public awareness and legal protections, youth who identify as LGBTQ continue to face disparities that stem from multiple sources, including inequitable laws and policies, societal discrimination and health plan and system practices. These disparities can result in limited access to needed services or can deter LGBTQ children and youth from seeking the timely, comprehensive, developmentally appropriate and quality physical and mental health care they need.

The impact of discrimination in the child and adolescent years has been linked to toxic stress and LGBTQ children and youth experience trauma at particularly high rates. When compounded over time, toxic stress predisposes children and youth to a higher likelihood of chronic disease in adulthood and other long-term negative health outcomes.[1] All children, regardless of sexual orientation or gender identity, should have health

[1] https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/discrimination#5

coverage that assures them access to all medically necessary, age-appropriate benefits to promote healthy child development. We urge CMS to include these protections in the final rule.

Provision of EHB (§ 156.115)

We support the proposal to eliminate the option for states to allow benefit substitution between EHB categories. When the 2019 payment rule announced these new flexibilities for states, we expressed our strong concern that it could leave children, particularly those with serious, chronic, or complex conditions, with limited access to needed services and their families with higher out-of-pocket costs. A Congressional Budget Office analysis[2] predicted that given more flexibility to design their own benefits, states would likely try to reduce premiums by scaling back key benefits for children, including mental health services, habilitative services and pediatric dental. We strongly urge CMS to include this provision in the final rule. We also provide the following recommendations to strengthen the EHBs for children.

Strengthening the pediatric services category. We applaud you for your commitment to strengthening coverage for individuals, families and children across the nation, particularly those who are most vulnerable. As you move forward with this work, we urge you to establish a federal standard for the pediatric services category that requires coverage of all age-appropriate preventive, diagnostic and treatment services that are medically necessary for children, including those who have a chronic condition, functional impairment, or significant or multiple health risks. We recommend that, at a minimum, the pediatric benefit category should be defined based either on the benefits provided in a state's CHIP plan or on the American Academy of Pediatrics' Scope of Health Care Benefits for Children[3] both of which are specifically tailored to children to meet their continuous, and changing, growth anddevelopmental needs. Under this approach, states should be required to assess the pediatric benefits that are included *and excluded* from their selected benchmark and use their CHIP benefits or those included in the Scope of Health Benefits to supplement as needed so the plan fully covers pediatric services.

Children are not little adults and require health care benefits distinct from those provided for adults. They must have access to medically necessary, age-appropriate services, regardless of their plan choice. Those services must be specifically suited to children's unique and continuous development and growth needs and must also include key therapies and devices that are now included in the habilitative services category of the EHBs. Habilitative services are especially important for children who may suffer from a condition at birth (such as cerebral palsy, autism or spina bifida) or from an illness or injury that prevents normal skills development and functioning. Receiving sufficient habilitative services that helps the child *acquire*, improve, or retain a skill or level of functioning that they did not previously possess can mean the difference between talking and not talking, walking and not walking, or needing special education and being able to join a regular classroom.

Unfortunately, the original benchmark approach was not developed with children in mind and does not take into consideration children's unique needs, unlike Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit standard and the benefits in state CHIP plans. Children often need services with greater frequency and intensity than adults, so certain benefit limits (for instance, limits on number of visits, frequency of service or device replacement, etc.) established for adults may be inappropriate for children who are continuing to develop and grow.

---

[2] Congressional Budget Office. Cost Estimate H.R. 1628, American Health Care Act of 2017 (as passed by the House of Representatives on May 4, 2017), pp. 7.

[3] Scope of Health Care Benefits for Children From Birth Through Age 26. Committee On Child Health Financing Pediatrics Jan 2012, 129 (1) 185-189; DOI: 10.1542/peds.2011-2936.

This includes children's mental and the behavioral health care needs spanning the continuum of care such as promotion of mental health, prevention and early identification of behavioral health issues, assessment, referral, treatment across a range of settings, and management/co-management of behavioral health issues. Solutions for adults are not the same as solutions for children. For children, the goal of treatment for all levels of care is focused on maximizing functioning of the child, reducing distress for the child and family, and prevention of adult morbidity.

Given the impact of the COVID-19 pandemic on children's mental health, which has exacerbated challenges children faced prior to the pandemic, we urge CMS to ensure that the mental health category of EHB include meaningful access to pediatric mental health benefits across the continuum of care and in a range of settings, including in the pediatric primary care setting. CMS should expand health care coverage and payment for enhanced services such as integrated mental health care and supportive services. Additionally, Exchange plans should cover trauma-informed care services, including all necessary screenings, diagnosis, office-based management, counseling, case management, community collaboration, and home visiting.

We look forward to working with you to strengthen the pediatric EHB to ensure that children have adequate, age-appropriate coverage that is representative of all their health needs. The range of covered services available in each of the EHB categories, such as rehabilitative and habilitative services, pediatric services including mental health, dental and vision, and others, must provide a level of benefit protection that is vital to children's long-term health, well-being and future productivity.

Refine EHB Nondiscrimination Policy for Health Plan Designs (§ 156.125)

Our organizations also support the CMS proposal to refine its existing nondiscrimination policies with "a clear regulatory framework." Specifically, CMS proposes that a nondiscriminatory benefit design that provides EHB must "incorporate evidence-based guidelines into coverage and programmatic decisions and rely on current and relevant peer-reviewed medical journal article(s), practice guidelines, recommendations from reputable governing bodies, or similar sources."

This policy change will help ensure that child and adolescent enrollees have more equitable access to medically necessary care across different plans and insurers. Specifically, this policy change means that children and adolescents cannot face plan limits—without a medical basis—to a certain number of visits, provider type, or their capacity to attain a certain functional status. Absent these changes, children and youth with special health care needs and disabilities who need timely access to critically important services are at risk of facing barriers due to plan designs that lack an evidence basis and instead rely on perception and tools that discriminate, such as Quality Adjusted Life Years (QALY). Under the current rules insurers may: set caps on physical or occupational therapy sessions for specific diagnoses regardless of medical necessity, prohibit or cap access to home health care and durable medical equipment for specific diagnoses regardless of medical necessity, or use a tool that estimates the value, and therefore the approval, of treatment for a child that subtracts or discounts that value simply because the child has a disability.

We support the "clear regulatory framework" outlined in the proposed rule and urge you to finalize this proposal.

Network Adequacy (§156.230)

We are pleased that CMS plans to reestablish the federal reviews of network adequacy, beginning in plan year 2023. An active federal role in the review and oversight of provider networks, based on a strong framework of

standards, is critical to helping ensure that families are not faced with exorbitant out-of-pocket expenses because they must seek out-of-network care for their child if there is not an appropriate in-network provider. To that end, we urge you to also establish minimum, uniform procedural standards for the state-based exchanges, as well. A child's access to an appropriately trained pediatric provider should not be a function of whether their state has a federally-facilitated or state-based Exchange.

The Notice includes some important first steps towards assuring that children and families have access to the in-network care they need when they need it. In particular, we strongly support the establishment of specific standards for pediatric primary care providers and behavioral health providers and the requirement that providers must be contracted within the lowest cost-sharing tier in tiered networks. We are also pleased that the set of metrics has been somewhat expanded to include wait times for a subset of providers, including behavioral health.

However, it is absolutely critical that stronger pediatric-specific standards are established for the QHPs. We respectfully remind you that children are a unique population, and their providers are different than those for adults. Pediatric providers have specific training, experience and expertise that equips them to meet the physical, mental, and developmental health needs of all children, including those who have serious, complex, or chronic health conditions or special health care needs.

Pediatric-specific standards would allow for an assessment of provider networks to ensure the inclusion of trained and experienced in-network pediatric providers capable of providing appropriate care—from well-baby care to care for children and youth with special health care needs, including those with serious, chronic, or complex conditions. Inadequate and limited networks that do not include this range of providers may result in care delays with poor health outcomes that ultimately cost insurers and consumers more. Appropriate pediatric standards should:

- Ensure that QHP networks are capable of providing pediatric services (both physical and mental health) for all levels of complexity, including for rare conditions, without administrative or cost barriers for children and families.
- Only allow out-of-network arrangements as an exception for extremely rare services or when timely access to the type of provider a child needs cannot be assured.
- Not allow a child to be penalized by the health plan through extra cost sharing or administrative hurdles in the rare circumstance when that child must use an out-of-network provider.

To meet these goals and assure that children can get timely and age-appropriate care, network adequacy standards must be developed for the full range of board-certified pediatric specialties and subspecialties.[4] The standards also must assure that networks include one or more appropriate pediatric hospital providers and reflect the fact that teams of pediatric specialists are typically concentrated near children's hospitals, underscoring the regional nature of pediatric specialty care for high-acuity conditions.

[4] Including, but not limited, access to pediatric Allergy/Immunology, Hospital Medicine, Dermatology, Neurology, Surgery, Adolescent Health, Child Abuse and Neglect, Hospice and Palliative Care, Transport, Urgent Care, Otolaryngology, Developmental-Behavioral Pediatrics, Cardiology, Critical Care, Emergency Medicine, Endocrinology, Gastroenterology, Hematology-Oncology, Infectious Diseases, Nephrology, Pulmonology, Rheumatology, Obesity, Sports Medicine, Plastic Surgery, Neurological Surgery, Genetics, Ophthalmology, Anesthesiology, Orthopedics, Radiology, and Urology.

Time and distance standards and appointment wait times—It is critical that quantitative network adequacy metrics enhance, rather than impede, children's timely access to the most appropriate provider for the care they need on an in-network basis. We support the use of time and distance metrics as a generally appropriate measure of a network's pediatric primary care capacity. However, time and distance cannot account for the many children who travel long distances and across state lines to receive necessary care from appropriate pediatric specialty providers, including children's hospitals equipped to meet their unique tertiary and quaternary medical needs. A study in the June 2018 issue of Health Affairs[5] found that nearly half of pediatric specialty hospitalizations took place outside of adult-focused distance standards. Similarly, an earlier Children's Hospital Association analysis found that approximately 50% of children nationwide would not have access to the services of an acute care children's hospital if adult Medicare Advantage time and distance standards are used. The use of time and distance standards as the sole metric for network adequacy would place children at risk of delayed services or may lead them to care in settings ill-equipped to address their pediatric service needs.

Rather than a sole reliance on time and distance, we recommend a comprehensive, multi-faceted set of quantitative standards specific to pediatrics. Those measurable factors include, but are not limited to, wait times (as proposed in the Notice for behavioral health providers, but applied to all pediatric specialties); enrollee ratios by specialty; geographic accessibility; geographic population dispersion; and minimum appropriate providers available to meet the needs of children with special health care needs, including those with limited English proficiency, and diverse cultural and ethnic backgrounds.

In addition, we urge CMS to strictly limit a plan's opportunity to provide a justification for an inadequate network in lieu of assuring an adequate network. These types of justifications should only be accepted in very rare circumstances and for very rare health conditions. For example, plans must not be allowed to secure exceptions solely because the appropriate provider is in another state. Plans must be required to design networks that ensure access to appropriate in-network providers for all covered services and must not be allowed to rely on out-of-network arrangements, exceptions (justification) processes and other mechanisms that create barriers and burdens for sick children in need of care.

Furthermore, we respectfully remind CMS that an overly generous exceptions (justifications) process that impedes access to necessary care could be discriminatory based on health status and violate the non-discrimination provisions of the ACA. In order to avoid discriminatory practices, plans must be able to ensure that all enrollees have access to covered health services from a full range of in-network providers, including children's hospitals and other regional specialty providers.

We also urge CMS to implement strong, ongoing monitoring and analytical strategies. Oversight, including regular audits of plans' provider networks, is crucial to ensuring that children have access to timely care and the in-network providers they need, particularly pediatric specialists. The oversight and monitoring of plan networks must include procedures to identify and address pediatric provider network gaps or access barriers, including wait times and transportation complexities. As part of that oversight, plans' consumer-facing information regarding their networks must be reviewed regularly to ensure that it includes accessible and up-to-date provider directories and clearly explains cost-sharing responsibilities, approval processes for out-of-network services, and appeals procedures for denied services. Plans also should be able to provide consumers with their provider selection standards, including the use of quality as a factor in network design and/or any

[5] See Children's Hospital Association. Implications of adult network adequacy standards on children's access to pediatric specialty care, June 2018.

emphasis on centering network design on lower-cost providers, which may exclude some more highly specialized and trained providers that children might need.

Finally, we urge you to consult closely with a spectrum of pediatric provider/facility types, caregivers, child health advocates, and health plans to develop workable and effective pediatric standards and review process. That expertise can help you design a framework that takes into account the full range of children's physical health, mental health and developmental needs, geographic challenges, and the regionalization of pediatric specialty care. Furthermore, as there is currently no state-of-the-art knowledge regarding network adequacy metrics for pediatrics, the standards development and implementation processes must be nimble enough to adapt as health care delivery and population needs change.

Telehealth Services—We agree that future consideration should be given to the role of telehealth in network adequacy but urge you to consider telehealth as a supplement to, rather than a substitute for, appropriate in-network providers. During the coronavirus pandemic, telehealth emerged as a vital health care service delivery tool for providers, patients and families. It will continue to be critical to providing necessary care beyond the pandemic. Pediatric providers have implemented a range of telehealth technologies to meet the needs of their patients ranging from texting families the results of COVID-19 tests, conducting aspects of well-child visits, delivering behavioral health services and providing in-hospital consultive care via telehealth. We look forward to working with you on an approach to the incorporation of telehealth into network adequacy standards that are appropriate for all children, particularly those with serious, complex and/or chronic conditions or special health care needs.

Essential Community Providers (§ 156.235)

We thank CMS for continuing to recognize the importance of essential community providers (ECPs) in meeting the needs of underserved communities throughout the country and applaud you for increasing the minimum ECP participation threshold from 20 to 35%. We strongly recommend that HHS require plans to meet this standard for each category of ECP, rather than for all ECPs take as a whole, to help ensure that enrollees have better access to the full range of services that the ECPs provide. ECPs, including children's hospitals, play a particularly critical role in the care of low-income children and children with serious, complex, or chronic conditions or special health care needs. These children rely upon a comprehensive and diverse range of medical and ancillary services to meet their unique developmental and growth needs, which ECPs are designed to provide.

At the same time, we recommend that you consider ways to raise the standard higher as we believe that, regardless of the established minimum, most plans will achieve that standard and go no further. Networks without a sufficient number and scope of ECP types could lead to gaps in care. Delays in care can be particularly detrimental to children's health, resulting not only in poor health outcomes, but additional costs to the health care system and long-term costs to the nation's economy.

We also remind CMS of the importance of plan oversight to ensure that QHPs are, in fact, meeting the ECP standards. That oversight must include procedures to monitor, identify, and address gaps in ECP contracting, assess the validity of "good faith" offers, and review provider directories for accuracy.

Non ACA-compliant coverage options

As you continue your work to strengthen health care coverage and access for children and families, we urge you to rescind the final rules that extended the availability of short-term limited duration insurance plans,

association health plans and other non ACA-compliant plans, such as health care sharing ministries. These plans, which do not have to meet the ACA's insurance consumer protections, such as the prohibition on medical underwriting and pre-existing conditions exclusions, can have serious negative implications for children's health and health care. They can result in exposure to higher costs due to annual and/or service-specific limits, coverage denials, and limited access to appropriate pediatric providers. Family confusion about the difference between ACA-compliant plans and these other options may lead to the purchase of a plan that does not cover necessary pediatric services, including vision and dental, habilitation or mental health services as well as long term gaps in coverage. We urge you to move forward as quickly as possible to limit access to these plans and to fully educate the public about their shortcomings.

In conclusion, we appreciate the opportunity to comment on the proposed rule and applaud you for your efforts to strengthen private coverage through the Exchanges. We look forward to working with you to ensure that those efforts strengthen children's access to timely and appropriate quality health care and health care coverage.

Sincerely,

American Academy of Pediatrics
Children's Defense Fund
Children's Hospital Association
Family Voices
First Focus on Children
Georgetown Center for Children and Families
March of Dimes
National Association of Pediatric Nurse Practitioners