September, 30, 2015

Dear Sir or Ms.:

As an organizations dedicated to the health of children and families, we are writing to respectfully urge you to consider the unique health care needs of children, particularly children with special health care needs, as you review state Essential Health Benefit (EHB) benchmark choices. We remain concerned that the EHB benchmark approach does not ensure children and youth have access to a comprehensive set of benefits that meets their needs. Therefore, it is especially important that CMS scrutinize proposed 2017 benchmark plans for their specific approach to benefits for children, including but not limited to the pediatric services and rehabilitative and habilitative services categories. We urge you to consider the following framework for your benchmark review:

- **Use each state's Children's Health Insurance Program (CHIP) as the baseline for your review of the pediatric benefits in the benchmark.** We urge CMS to, at a minimum, use each state's Children's Health Insurance Program (CHIP) benefit package as the basis for a cross-walk with the state benchmarks to determine which benefits are include and excluded. The small group plans that largely serve as the EHB benchmarks were not developed with adequate consideration of children's needs, unlike Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit standard and the benefits in state CHIP plans. Both EPSDT and CHIP plans have a robust benefits package that assures children receive all the services they need to maintain and improve their health as they grow and develop. In contrast, studies[1] have documented the significant gaps in pediatric services covered by plans subject to the EHB requirement, especially when compared to the child-appropriate benefits under CHIP. Those gaps can be seriously detrimental to a child's healthy development and well-being.

- **Ensure that the new federal definition of habilitative services and devices is appropriately incorporated into the benchmark and enforced to meet children's unique health care needs.** We applaud you for the establishment of a uniform definition of habilitative services and devices – a vitally important first step to ensuring that children have access to the full range of services they need to attain and maintain their highest developmental potential. We urge you to carefully review the plans to confirm that the components of the definition are fully incorporated into the benchmarks in a manner that

[1] See: Government Accountability Office (GAO), Children's Health Insurance: Coverage of Services and Costs to Consumers in Selected CHIP and Private Health Plans in Five States (March 2015)
Health Affairs: The ACA's Pediatric Essential Health Benefit Has Resulted In A State-By-State Patchwork Of Coverage With Exclusions (Sept. 2015)
The Wakely Consulting Group, Comparison of Benefits and Cost Sharing in Children's Health Insurance Programs to Qualified Health Plans (July 2014)

ensures that children who need habilitative services and/or devices have appropriate and timely access to those benefits.

- **Ensure that the benchmark plans meet the requirements of the Affordable Care Act (ACA) to provide pediatric oral and vision care.** We continue to be concerned regarding inadequate coverage of pediatric dental and vision services. The use of CHIP or the Federal Employees Dental and Vision Program (FEDVIP) as the basis for supplementing this benefit when the benchmark is lacking provides a strong basis for these important benefits. Therefore, the benchmark review should be rigorous enough to assess whether appropriate supplementation occurred and whether the scope of these benefits is child-appropriate.

- **Review the benchmarks with particular sensitivity to the potential that benefit designs may violate important nondiscrimination protections of the Affordable Care Act (ACA).** We want to emphasize the potential discriminatory aspect of benchmark designs that impose arbitrary age limits or other limiting factors based on disability or health condition. In particular, arbitrary limits on the scope of benefits that result in inadequate access for children with special health care needs or coverage of certain services constricted by age limits would be in direct violation of the ACA's Section 1557 and proposed implementing regulations. We provide a number of examples below of inadequate coverage for children in the benchmarks that would warrant special scrutiny in this regard.

We respectfully submit the following specific observations and recommendations regarding the proposed 2017 benchmarks.

Inclusion of comprehensive pediatric services

We urge CMS to review the benchmark plans carefully to ensure that pediatric services are covered appropriately. First, we reiterate our recommendation that the agency's review of pediatric coverage include a cross-walk with the state's CHIP benefit package. The CHIP benefits are specifically tailored to children and meet their continuous, and changing, growth and developmental needs. Children are not little adults and require a set of health care benefits distinct from those provided for adults. Failure to ensure adequate and appropriate pediatric-specific benefits can result in life-long health consequences that generate extensive and avoidable costs.

An informal review of the proposed benchmark plans across the EHB categories reveals numerous instances of inadequate coverage for children, including coverage with arbitrary visit limits or limits on service frequency. Therefore, a review of the benchmarks with a pediatric lens should include an assessment of all ten EHB categories, in addition to the pediatric services and habilitative services and devices categories. 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.[2]

[2] See the American Academy of Pediatrics Scope of Health Care Benefits for Children policy statement.

We also urge you to consider providing additional guidance regarding the design of the plan summaries and related materials to ensure consistency, accuracy and clarity. Our benchmark review reveals that plan documents frequently contain confusing information about covered services, limits and exclusions, or exclude this information altogether. Furthermore, there are numerous inconsistencies in the type and format of information that is provided by the benchmark plans. We recommend standardizing the benchmark reporting process in order to make compliance with EHB clear and to ease your data collection process in the future. Additional federal guidance on plan documents will provide consumers with the information they need to make informed decisions regarding their coverage. At the same time, health plans will have a clear and consistent framework in the benchmarks on which to base their specific plan designs.

We provide you with several illustrative examples of inadequate coverage of important services for children.

- **Audiology services** are an important component of a developmentally-appropriate pediatric benefits package. Hearing loss can affect a child's ability to develop speech, language, and social skills and early intervention is critical to ensure a child's proper development. In order to make sure that children with hearing loss reach their full potential, benchmark coverage must include screenings; technology to help with communication, such as hearing aids and cochlear implants; and additional services to promote language development, such as speech therapy.

  Our informal review of state benchmark plans revealed a number of concerns regarding coverage of pediatric audiology services. For example:

  - Many state benchmarks limit hearing screenings to newborns only, though hearing loss may not be identified until later in the child's development
  - Many state benchmarks do not specify whether hearing loss would qualify a child for services such as speech therapy, and if so, what limits to those services would apply. Arbitrary limits on these services could delay language development in a child with hearing loss who may require significantly more speech therapy visits, especially during the critical language development year.
  - Of the limited number of benchmarks that cover hearing aids for children (slightly more than half), some do not cover the associated technologies that are required to make the hearing aids work (such as ear molds)

- **Well-baby and well-child visits** allow health care providers, with parents, to monitor a child's development to ensure the child's physical, mental, social and emotional well-being. While every state benchmark we reviewed clearly covered well-baby visits, we found coverage of well-child visits much more difficult to assess. For example:

  - At least six state benchmarks that stop all well-child visits before age five
  - At least eight state benchmarks stop all well-child visits before age ten

- Many state benchmark plan documents identified coverage of preventive benefits, but without enough specificity to clearly determine whether a well-child visit would be covered
- Many benchmark documents reference adherence to a national standard, like that of the American Academy of Pediatrics Bright Futures, but they do not always comply with those standards

- **Home health services** (such as inhalation therapy, cleaning of ventilators, nutritional guidance, or medical and surgical supplies) are an important aspect of care for children with serious, chronic or complex conditions. These services can help children avoid hospitalization, engage with school and other community activities, and grow and develop to their full potential even as they deal with their medical condition.

  Our informal review of the state benchmark plans identified a number of problematic examples of limited coverage which could either prevent a child from being at home or otherwise impede access to these needed services.[3] These include:

  - Some state benchmark plans only cover home health services for individuals who are homebound and unable to leave their home. This requirement means that a child with a serious, chronic or complex condition cannot attend school or engage in other activities and also receive needed home health care services.
  - At least one state benchmark will not cover home health care services if the plan determines that the care can be "appropriately provided in a Plan Facility or Skilled Nursing Facility, if [the plan] offers to provide that care in one of these facilities." Under this benchmark, a child would not be allowed to live at home and receive services such as occupational, physical or speech therapy, oxygen therapy, etc.
  - Several benchmarks require preauthorization of prescribed home health care services that could be particularly burdensome. For example, one state requires the family to call the plan's medical director after their physician recommends home health services at least one business day prior to the planned beginning of those services. This type of requirement can delay a child's return to the home or can result in fragmented care.

Coverage of habilitative services and devices that meet children's developmental needs

We urge CMS to conduct a thorough review of the coverage of habilitative services and devices in the benchmarks to ensure that they include adequate coverage for children, including appropriate services and devices that help a child keep, learn, or improve skills and functioning. Receiving sufficient habilitative services and devices that help 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. Therefore, the CMS benchmark review must ensure that:

[3] The GAO analysis of health plan coverage compared to CHIP coverage also observed limitations of home health care benefits in the private plans in the states included in the analysis. Children's Health Insurance: Coverage of Services and Costs to Consumers in Selected CHIP and Private Health Plans in Five States (March 2015).

- States have incorporated, at a minimum, the uniform definition of habilitative services and devices in the proposed benchmarks

- The habilitative services benefit includes, but is not limited to, physical and occupational therapy, speech-language pathology, behavioral health services, audiology, rehabilitation medicine, and developmental pediatrics

- The habilitative devices benefit includes, but is not limited to, durable medical equipment (e.g., wheelchairs and related accessories), orthotics, prosthetics, low vision aids, hearing aids, augmentative communication devices that aid in hearing and speech, and other assistive technologies and supplies

In addition, we ask CMS to pay particular attention to any limits that may be imposed on the habilitation benefit. Coverage of habilitative services and devices without arbitrary age, visit or other limits is 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. For example, it may be difficult to measure progress for a child who is developing a skill for the first time and services for that child may be needed for an extended period. For some children with progressive conditions, progress may be measured by a reduced rate of loss of function or maintenance of existing skills. Furthermore, it may not be possible to determine, with certainty, the limits of the child's capacity – whether, for example, more speech therapy will enable the child to develop stronger verbal skills. In addition, as they grow or their skills develop, children will need frequent replacements of devices, such as wheelchairs, glasses, auditory aids, orthotics, prosthetics, and augmentative communications devices.

Our own review of the coverage of habilitative services and devices in the proposed benchmarks raises some serious concerns regarding state implementation of this critically important benefit for children and youth with special health care needs. For example:

- Eight state benchmarks do not include coverage for habilitation at all

- More than two-thirds of the state benchmarks impose arbitrary visit limits on physical therapy (PT), occupational therapy (OT) and/or speech therapy (ST) visits. The allowed number of visits varies widely, signaling the arbitrary nature of the limits, and the lack of a medical necessity standard.

- Close to 10 state benchmarks impose combined visit limits that apply to OT, PT, and ST. The unique developmental needs of an individual child cannot be met when arbitrary visit limits are not only imposed on these major therapies, but apply in combination to all three.

- Some benchmarks only cover habilitation for specific conditions; others impose age limits. For example:

  - A handful of benchmarks only cover habilitation for children with autism; one state benchmark covers habilitative services only for children up to age 9 with autism, and another only covers habilitation for children ages 2-8 with autism
  - Some states only cover habilitation for conditions resulting from an injury or illness; conversely, some states only cover services for the treatment of congenital or genetic birth defects

- Coverage of hearing aids for children is inadequate in most states:

  - Almost half of the state benchmarks do not cover hearing aids
  - Of the remaining states, at least 15 benchmarks only cover hearing aids for children, but impose arbitrary age limits that range from 15 to 25 years of age
  - A few state benchmarks cover hearing aids only if the child is enrolled in school
  - At least one state only covers hearing aids for newborns
  - In several states, hearing aids can only be replaced every 4 or 5 years, which does not meet the developmental needs of children as they grow

- One state covers the cost of only one prosthetic device, per limb, per lifetime, which does not allow a child to get a replacement as they grow

- Coverage of wheelchairs is inadequate for children in many of the benchmarks that we reviewed:

  - Wheelchair coverage is not always explicitly indicated in plan documents
  - In at least one state benchmark, wheelchair replacement is not covered when the replacement is needed because the enrollee's condition has changed
  - One state does not cover wheelchairs because a wheelchair "would ordinarily be of use to a person in the absence of a medical need"
  - Wheelchair replacement and/or repair is not covered or specifically addressed in the benchmark plans of several states

On the other hand, we are pleased that there are a few benchmarks with relatively good coverage of habilitation. For example:

- Close to one-third of the states do not impose arbitrary visit limits on habilitative services; one state includes a specific reference to medical necessity when delineating how the benefit is provided

- At least one state benchmark acknowledges that 100 percent functionality may not be possible for enrollees who need habilitative services and devices. This is an important recognition that children may not be able to achieve 100 percent functionality but can still attain and maintain a level of functioning as a result of habilitation.

- At least two benchmarks provide or reference a broader spectrum of services and devices under the habilitation benefit beyond the PT, OT, and ST standard in most states

- Three states have no limits on hearing aid replacements for children
- Several benchmarks cover wheelchair replacements when needed as a result of the growth of a child

Finally, while we were pleased that the federal definition of habilitation includes devices, pursuant to the 2016 Notice of Benefits and Payment Parameters, we are extremely concerned that the benchmark plans do not specifically identify habilitative devices in their plan documents. Instead, devices that could be considered habilitative in nature are included in the documents under the durable medical equipment (DME) benefit. Not only are these references to devices confusing for consumers, they could result in lack of coverage of some important habilitative devices, such as speech-generating device for individuals with voice disorders, which are typically not considered to be DME.

Therefore, we believe CMS should identify, in future regulatory guidance, a certain minimum set of basic habilitative services and devices that plans should cover. Clearly, the state benchmark coverage of habilitation varies significantly among plans and will not, as currently formulated, meet children's developmental needs. Without a minimum set of identified services, there is no firm mechanism for CMS or a state to determine whether a plan's habilitative services benefit is adequate to meet beneficiaries' needs.[4]

Access to pediatric dental and vision benefits

We urge CMS to ensure that state benchmarks cover the full range of pediatric dental and vision services. First, CMS should include a specific review of the pediatric dental coverage in the state benchmarks to ensure that children have access to age-appropriate dental services, including regular dental check-ups, basic dental care, major dental care, and medically-necessary orthodontia.

Second, we urge CMS to review the vision coverage in the benchmark plans to ensure that the critical components of pediatric eye care are covered. Access to high-quality and necessary optical, medical, and surgical eye care during childhood is a cost-effective strategy for ensuring long-term vision and eye health. Regular developmentally-appropriate screenings; vision care; referrals to tertiary medical/surgical eye care as needed; and treatment (eyeglasses, etc.) all play an important part in ensuring children's ocular and visual health. Childhood vision deficits, if not detected early, may lead to lifelong uncorrectable vision conditions with the potential to affect all aspects of life and negatively impact a child's development, ability to learn and succeed in school, athletic performance, and self-esteem.

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[4] The habilitative services benefit should include, but not be limited to, physical and occupational therapy, speech-language pathology, behavioral health services, audiology, rehabilitation medicine, and developmental pediatrics. Habilitative devices should include, but not be limited to, durable medical equipment (e.g., wheelchairs and related accessories), orthotics, prosthetics, low vision aids, hearing aids, augmentative communication devices that aid in hearing and speech, and other assistive technologies and supplies.

We know that the vision coverage under FEDVIP and CHIP provides the comprehensive vision coverage that children need. Therefore, CMS should review the benchmarks to confirm that they have supplemented the benchmark with the benefits under one of those plans. If not, CMS should pay particular attention to this benefit to ensure that comprehensive pediatric vision services are, indeed, covered.

We are pleased that our review of the state benchmarks finds that there are states that have supplemented their benchmarks with the vision benefits in FEDVIP or CHIP and have comprehensive coverage. However, there are still too many benchmarks that are not adequately covering pediatric vision care:

- A number of states are not supplementing pediatric vision services even though the benchmark offers inadequate coverage of these services for children

- At least three states either do not cover eyeglasses or offer only limited coverage. Coverage of vision screening, without coverage of eyeglasses or other appropriate treatment, can cause long term harm to a child's overall visual health.

- In at least six states, it is unclear how pediatric vision services are covered because the benchmark plan documents do not provide a list of covered vision services

Ongoing monitoring of EHBs

We are pleased that CMS intends to collect data on the EHBs to help guide any future changes in the implementation of this important aspect of the ACA. We ask that you include specific data collection elements in your evaluation of state implementation to assess children's coverage, including their access to the habilitation benefit. In that regard, we strongly urge CMS to closely monitor and evaluate the implementation of the habilitation benefit to track the types of services and devices covered by plans and the impact of coverage limits on access to appropriate care. CMS monitoring and oversight of children's access to all aspects of the EHBs is an important tool to assess gaps in services or obstacles to care and determine if further rulemaking or policy changes are warranted in the future. This type of information also is particularly important to families of children with serious, chronic or complex medical conditions who need to understand if and how their plan will meet their child's need.

Again, we thank you for your leadership on the implementation of the ACA. We look forward to working with you to ensure that children's coverage continues to be strengthened as implementation moves forward.

About AMCHP: The Association of Maternal & Child Health Programs is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs. AMCHP's members come from the highest levels of state government and include directors of maternal and child health programs, directors of programs for children with special health care needs, and other public health leaders who work with and support state maternal and child health programs.

Our members directly serve all women and children nationwide, and strive to improve the health of all women, infants, children and adolescents, including those with special health care needs, by administering critical public health education and screening services, and coordinating preventive, primary and specialty care. Our membership also includes academic, advocacy and community based family health professionals, as well as families themselves. For additional information, please reach me at 202-775-0436 or bewig@amchp.org.

Sincerely,

/s/

Brent Ewig, MHS

Director of Policy