October 6, 2016

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

Re: Comments on HHS Notice of Benefit and Payment Parameters for 2018 Proposed Rule, CMS-9934-P

Dear Madame Secretary,

We, the undersigned members of the Consortium for Citizens with Disabilities, thank you for the opportunity to comment on this important rule. The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

Guaranteed Renewability (§147.106)

CCD shares the concerns of the Medicare Rights Center with regard to Guaranteed Renewability and Anti-Duplication as it pertains to the transition from QHPs to Medicare. Many people receiving Social Security Disability Insurance will obtain QHP coverage during their 24 month Medicare waiting period. Many other people with disabilities not receiving SSDI may also become eligible for Medicare while enrolled in a QHP. We believe that these individuals should retain the ability to choose the health insurance coverage most suitable, and that CMS should endeavor to ensure that people have adequate notification and information to make an informed choice.

Pre-Existing Condition Insurance Plan Program (§ 152.45)

We appreciate that CMS is trying to ensure that people previously on the Pre-Existing Condition Insurance Program (PCIP) maintain insurance without disruption. However, coverage under the PCIP ended on April 30, 2014.[1] The PCIP provided crucial coverage for people with disabilities and chronic conditions in the years between the enactment of the Affordable Care Act and opening of the Health Insurance Marketplaces. It is unclear to us if some individuals remain enrolled in the PCIP, but CCD understands that all PCIP enrollees should now be enrolled in a QHP or other MEC. CCD would not support efforts to revert to PCIP coverage.

[1] https://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/Downloads/PCIP-fact-sheet-4-24-2014.pdf

Reinsurance, Risk Corridors, and Risk Adjustment (§ 153)

CCD recognizes the complexity of the reinsurance, risk corridors, and risk adjustment programs. However, we do wish to stress that methodologies should appropriately accommodate for the needs of individuals with disabilities and chronic conditions. The alternative would mean applying an unfair standard of care to these populations (i.e. a standard of the average patient, rather than a more complex standard), thus increasing the chances of stinting on patient care to those who need it most.

Standardized Options (§155.20)

As we noted in our December 21, 2015 letter commenting on the Notice of Benefit and Payment Parameters for 2017, CCD supports the intent to simplify the experience of shopping for a qualified health plan through standardized benefit options. However, we have concerns related to high deductible health plans, cost-sharing for habilitation, and specialty drug tiering.

High Deductible Health Plans
We are concerned about the inclusion of high deductible health plans (HDHPs) to the standardized options. HDHPs may attract consumers with low premiums, but are often a route to financial ruin for anyone who acquires a disability or chronic conditions. HDHPs have failed at achieving the policy aims for which they were devised. People enrolled in HDHPs do not utilize health care more efficiently or "smarter" because they have "skin in the game." Instead, enrollees use less health care across the board, including preventive or other necessary care. HDHPs also do not save money long term, instead provide *at best* short-term savings that disappear in the long-term.[2] Just like standardizing inadequate therapy benefits normalizes subpar services, standardizing HDHPs could further systematize this new benefit structure and confuse consumers. If CMS continues with a standardized HDHP, we encourage that CMS make very clear to consumers that HDHPs do not offer the protection from financial ruin that one might expect from traditional health insurance.

Habilitation
We continue to support the exemption of additional services from the deductible, including primary care and specialty visits, and we would like to urge HHS to add habilitative services to the list rather than limiting the exemption to rehabilitative services. Particularly for children with disabilities and chronic illnesses, coverage of habilitative services is critical. For those who may have a condition at birth, such as cerebral palsy, spina bifida or autism, or have experienced an illness or injury that prevents normal skills development and functioning (such as a brain injury), habilitative services should be available early and consistently for the best and most cost-effective outcome.

The Proposed Rule also adds three new sets of standardized options for the 2018 plan year (Tables 12,13 and 14). Table 13 is a set of standardized options designed to work in states that require that cost sharing for physical therapy, occupational therapy and speech therapy be no greater than the cost sharing for primary care visits. While these proposals only apply to the standardized option, CCD commends CMS in its attempt to align the cost sharing for physical therapy, occupational therapy and speech therapy with primary care visits. If finalized, these policies will increase consumer access and limit the financial barriers to therapy services.

[2] http://www.healthlaw.org/publications/search-publications/nhelp-federal-comments-to-health-indiana-1115-demonstrations#.V-A8pfkrLIU

However, in Tables 12-14, Proposed 2018 Standardized Options, CMS lists "Speech Therapy" and "Occupational Therapy/Physical Therapy" but does not list habilitative services, indicating that rehabilitative services are subject to a coinsurance but habilitative services are not. CCD requests clarification on this point, and suggests that both rehabilitative and habilitative services and devices in the Exchanges be exempt from co-insurance. We request:

- this exemption based on the understanding that habilitation and rehabilitation are to be treated the same;
- that occupational therapy and physical therapy be considered separate and distinct therapy services, similarly to how rehabilitative speech therapy is listed separately; and,
- that cost-sharing be reasonable in order to not be a barrier to consumers accessing necessary therapy services.

Prescription Drugs

With regards to prescription drugs, while we are pleased to see HHS' proposal to continue reasonable co-pays rather than co-insurance for most Simple Choices plans and tiers, we are concerned with the use of high co-insurance for all drugs on the "Specialty Drug" tier and in most bronze plan tiers. The use of coinsurance amounts to a total lack of transparency. As beneficiaries cannot access drug price information prior to choosing a plan to calculate the dollar amount they will have to pay, such cost-sharing designs significantly disadvantage individuals who rely on prescription drugs to manage their chronic conditions during the plan selection process and can be characterized as discriminatory.

Co-insurance often results in high beneficiary costs that place medications out of reach for most patients and reduces medication adherence. Frequently, issuers place a high number of drugs to treat an individual health condition on the specialty tier. This can result in discriminatory plan design. These plans that use adverse tiering are disproportionately forcing beneficiary cost sharing on prescription drug benefits and discourage beneficiaries with chronic conditions from enrolling. This is in violation of the strong non-discrimination provisions included in the ACA. Some issuers have successfully designed plans that limit patient cost-sharing to reasonable and affordable co-pays, and we encourage HHS to use the Simple Choice plans to lead issuers in this direction. Therefore, we strongly oppose the use of co-insurance for the "Specialty Drug" tier across all metal levels and in all tiers (except for generics) in the Bronze plans.

We are also pleased that most of the Simple Choice plans for 2017 exempt patient cost-sharing for prescription drugs from the deductible and suggest that be continued and expanded to bronze plans for 2018. We strongly believe that prescription medications should not be subject to a plan's deductible at any metal level and especially for plans with very high deductibles near or even equal to the maximum allowable out-of-pocket limit. Thus, we are disappointed that HHS is proposing to continue subjecting the cost-sharing for all medications except generics to the deductible in the Bronze Simple Choice plans. If medications are included in the Simple Choice bronze plan's $6,650 deductible, beneficiaries with limited income and resources will encounter cost barriers to accessing necessary medications. We are likewise concerned that HHS is proposing to remove the deductible exemption for specialty tier drugs at the Silver and 73 percent cost-sharing reduction (CSR) plans. Although the proposed addition of separate drug deductibles at these levels provides some protection, it may actually increase patient cost-sharing. Furthermore, while we strongly support not applying the deductible at all to any tiers of drug coverage under the 87 percent CSR, 94 percent CSR, and Gold plans, we are concerned that listing a separate $0 Rx deductible for these plans adds confusion for beneficiaries.

Consumer Assistance Tools and Programs of an Exchange (§ 155.205)

CCD shares the concerns and recommendations of the National Health Law Program with regards to aggregation of populations with Limited English Proficiency (LEP), including concerns about retaining taglines and alignment with section 1557. Specifically, we recommend that CMS:

1. Retain specific tagline requirements in § 155.205 rather than merely cross-reference to 42 C.F.R. § 92.8 or omit references.
2. Only allow aggregation if an entity documents that it would be a hardship not to aggregate due to increased costs (recognizing that the entity would not have costs in producing taglines since model taglines are available from HHS).
3. If aggregation is permitted, only allow it between states in which a controlled group offers marketplace plans.

General Standards for Exchange Notices (§ 155.230)

We are concerned about the proposed amendment in § 155.230(d)(3) that would allow an individual market exchange or SHOP to send required notices through standard mail if it is "unable to send select required notices electronically due to technical limitations." The new sub-section appears to be intended to give exchanges and SHOPs the flexibility to send notices to the general public by standard mail even if that means disregarding the preferred communication election for electronic delivery made by some members of the public. On its face, § 155.230(d)(3) appears to be in direct conflict with the obligation of exchanges and SHOPs under Section 504 of the Rehabilitation Act, the Americans with Disabilities Act of 1990, and Section 1557 of the Affordable Care Act to provide effective communication and requested alternative formats, including electronic delivery of notices and information, to people with disabilities. The "technical limitations" referred to in § 155.230(d)(3) clearly do not rise to the level of "undue hardship" or "fundamental burden" that would allow an individual state exchange to forgo meeting a request for electronic communications, or any other alternative format, and instead send standard print mail.

CMS appears to acknowledge the potential contradiction when it clarifies in the proposed rule's preamble at p. 61501 that "to the extent that a SHOP is required to provide notices in a particular format to meet its obligation to perform effective communication with an individual with a disability under the Americans with Disabilities Act of 1990 (42 U.S.C. Ch. 126), section 504 of the Rehabilitation Act, or section 1557 of the Affordable Care Act, a SHOP should comply with those requirements." However this acknowledgment is limited because it references SHOPs and not market exchanges, is provided in the narrow context of proposed § 155.230(d)(2) which refers to an obligation to provide notices electronically or by standard mail only, and is provided in the preamble only.

Since § 155.230(d)(3) applies so directly to the provision of electronic notices by individual market exchanges or SHOPS, we recommend an explicit clarification within the text of § 155.230 that "this subsection does not alter any covered entity's obligation to provide notices in alternative formats, including electronic formats, to individuals with disabilities under the Americans with Disabilities Act of 1990 (42 U.S.C. Ch. 126), section 504 of the Rehabilitation Act, or section 1557 of the Affordable Care Act." Moreover, we ask CMS to take this opportunity to clarify more broadly in the preamble that regardless of how a covered entity chooses to deliver its notices, current and potential exchange and SHOP consumers with disabilities may request all their notices and information in the alternative format of their choice and those requests should be met short of undue hardship. This would be helpful to

qualified health plans and other entities which may not be entirely familiar with the extent of their obligations under Section 1557, or fully understand the interaction between the annual NBPP rules when they appear to specifically govern notices, and the overarching effective communication provisions of Section 504. Individuals with disabilities who have effective communication needs cannot be expected to deal with a patchwork of different modes of communication because a covered entity is under the wrong impression that different standards apply, or have the burden to re-specifying their communication need every time a distinct notice or category of information is sent to them.

Finally, we note that at p. 61500 of the preamble, CMs refers to "feedback from SHOP consumers and issuers that electronic notices are the preferred method of communication" as the reason for the decision to make electronic notices the default method of communication for required SHOP Exchange notices. We support CMS's willingness to recognize consumer communication preferences as a motive for updating NBPP requirements. However, this highlights the sharp contrast between the agency's willingness to take account of the general Exchange consumer's communication preferences and the ongoing failure to even provide a place for consumers with disabilities to record their communication needs within the federal and individual market streamlined application forms. If the onus is on consumers with disabilities to express their need for alternative formats such as Braille, large font, electronic formats, or sign language formats, then covered entities such as the individual market exchanges, SHOPs, Qualified Health Plans, and the federal marketplace itself, must be both responsible for appropriately notifying consumers with disabilities of their right to such alternative formats, and for meeting those communication requests once expressed. Practically this requires a means of capturing the accommodation request and ensuring that the request is maintained as part of the consumer's file so that all notices and correspondence are consistently available in the needed format across covered entities and programs. All covered entities should therefore be clearly advised within the NBPP and through other guidance and technical assistance of their obligations on this front. We will be more than happy to work with CMS on this obligation to monitor for compliance and enforcement of this obligation across covered Exchange entities.

Special Enrollment Periods (§ 155.420)

We appreciate CMS' efforts to distinguish between misuse of special enrollment periods and the very low take-up rates of special enrollment periods. We are very concerned about the burden of additional verification processes on consumers, especially consumers with disabilities.

We also support the clarification and codification of the special enrollment periods listed in the rule. With regards to (d)(12), we urge CMS to explicitly include provider data in the list of material plan or benefit display errors on the Exchange Web site that can trigger a special enrollment period. For people with disabilities, access to specific providers or to specific types of providers in a health plan network is extremely important and errors in this information on the Exchange Web site could be as important as the errors about services provided or cost sharing information.

Compliance Review for QHPs (§ 155.715)

We strongly support HHS' clarification that it does have authority to impose remedies following a QHP's failure to cooperate with a compliance review. We are concerned to hear that some QHPs have delayed providing HHS necessary materials for such compliance reviews.

We also would urge CMS to pay particular attention in compliance reviews to ensuring that QHPs are

providing all Essential Health Benefits (EHB). We would specifically point to the Mental Health and Substance Use Disorder EHB as an example to be particularly scrutinized. In selecting benchmark plans, almost every state chose or defaulted to a small group plan, plans that historically have offered very limited mental health benefits. These plans were also not previously covered by the Mental Health Parity and Addiction Equity Act (MHPAEA) and most had coverage of mental health services that would not meet the requirements of parity. In an effort to comply with the parity and non-discrimination requirements of the ACA, benchmark plans were then supplemented with some mental health services. However, the medical necessity criteria, benefit exclusions, treatment limitations, use of utilization management, and cost-sharing and other financial requirements remain variable, resulting in continued parity violations as well as uncertainty about what is covered and inadequate coverage of mental health services. In addition, there have been numerous studies and press reports that QHP provider directories contain "phantom networks" of mental health providers.[3]

We also urge CMS to focus § 1557, the ACA's non-discrimination provision, as compliance reviews are conducted. Section 1557 prohibits health plan issuers from designing plans in a way that discriminates against individuals with disabilities and prohibits discrimination in making decisions about coverage, reimbursement rates, establishing incentive programs, and designing benefits. One very important form of disability discrimination for people with disabilities is the needless segregation of individuals with disabilities. To give effect to this part of the ACA's non-discrimination provisions, health plans must provide sufficient coverage services to prevent people from being served needlessly in segregated settings. For example, failure to cover services essential for people with disabilities to live in their own homes or in supportive housing would violate the nondiscrimination provision if it results in individuals being served in segregated settings, such as a hospital or nursing home.

Network Adequacy (§ 156.230)

We appreciate that health insurance customers need easily understandable information on the adequacy of networks offered by QHPs, and strongly support increased transparency on the Marketplaces. However, we are concerned that this proposal places too much emphasis on primary care, and that the focus on hospitals and primary care in determining network adequacy may have the opposite impact on people with disabilities and chronic conditions. We are concerned that when people with disabilities or chronic conditions see a network labeled "Broad" they will assume that the network will have many providers that provide a broad range of specialties. By focusing on primary care, the opposite may be true. A network labeled "Broad" could easily have many primary care physicians but few specialists ready to treat people with disabilities and chronic conditions. This effect could also be exaggerated over the years as issuers respond to the incentive focus on primary care physicians and hospitals in their networks, but not specialists or other outpatient specialty clinics, in order to look better to consumers on the Marketplace.

---

[3] *See* AMERICAN PSYCHIATRIC ASSOCIATION, APA POLL FINDS ACCESS TO CARE STYMIED BY PHANTOM NETWORKS IN DC, PSYCH NEWS DAILY MAIL (5/17/2015) available at http://www.psychnews.org/update/2016_apa_daily_4d.html; MENTAL HEALTH ASSOCIATION OF MARYLAND, ACCESS TO PSYCHIATRISTS IN 2014 QUALIFIED HEALTH PLANS (Jan. 26, 2015) available at http://mhamd.org/wp-content/uploads/2014/01/2014-QHP-Psychiatric-NetworkAdequacy-Report.pdf; MENTAL HEALTH ASSOCIATION OF MICHIGAN, A 2014 ANALYSIS OF 88 MICHIGAN INDIVIDUAL HEALTH INSURANCE POLICIES FOR COMPLIANCE WITH MENTAL HEALTH PARITY (Jan. 2015) available at http://www.mha-mi.com/wp-content/uploads/2015/02/PARITY_REPORT_2014_SPEC_PROJ_FINAL.pdf; MENTAL HEALTH ASSOCIATION OF NEW JERSEY, "MANAGED CARE ADEQUACY NETWORK REPORT (Sept. 15, 2014) available at http://www.mhanj.org/wp-content/uploads/2014/09/Network-Adequacy-Report-Final.pdf.

We recommend that CMS add a measure of specialty care to the three already indicated specialties and measure broadness in the same way: comparing the number of providers in the network to the total number providers in other QHPs in that county. We appreciate that CMS plans to include additional specialties and facilities in the future, and recommend that CMS include them now. Specialties should include pediatric and adult neurologists, cardiologists, gastroenterologists, developmental-behavioral pediatricians physical, speech, and occupational therapists, orthopedists and prosthetists, physiatrists, and other specialists that serve people with disabilities.

CMS should also measure network breadth based on the providers actually participating in the network, not those listed by the issuer as participating. Unfortunately, the providers actually participating in a network differ alarmingly from those providers listed in the provider directory by the health plan issuer. Enforcement actions such as direct testing of a provider network could also inform network breadth ratings.

Surprise Billing (§ 156.230(e))

CCD strongly supports the protections against "surprise bills" codified at §156.230(e) that CMS will implement for benefit year 2018. As we stated in our December 21, 2015 letter commenting on the Notice of Benefit and Payment Parameters for 2017, we still recommend that CMS modify this provision to account for lack of accessibility. Specifically, if a consumer were forced to seek out-of-network care because he or she could not access any of the in-network facilities, any cost-sharing that he or she incurred would be subject to the maximum out-of-pocket limit and he or she would not be subject to balance billing.

Thank you for the opportunity to comment on this important regulation. For further information, please contact Julie Ward, Health Task Force co-chair at ward@thearc.org or 202-783-2229.

On behalf of:

American Association on Health and Disability
American Music Therapy Association
American Occupational Therapy Association, Inc
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
Association of University Centers on Disabilities
Autism Speaks
Brain Injury Association of America
Christopher and Dana Reeve Foundation
Disability Rights Education and Defense Fund
Easterseals
Epilepsy Foundation
Family Voices
National Alliance on Mental Illness
National Association for the Advancement of Orthotics and Prosthetics
National Association of State Head Injury Administrators
National Disability Rights Network
National Multiple Sclerosis Society
The Arc of the United States

United Cerebral Palsy
United Spinal Association

Other Supporting Organizations

Lakeshore Foundation