



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

February 19, 2019

VIA ELECTRONIC SUBMISSION

The Honorable Alex Azar
Secretary, U.S. Department of Health and Human Services
200 Independence Ave SW
Washington, DC 20201

**RE: Public Comments on Notice of Benefit and Payment Parameters for 2020
(RIN 0938-AT37, CMS-9926-P)**

Dear Secretary Azar:

The co-chairs of the Consortium for Citizens with Disabilities (CCD) Health Task Force write in response to the proposed rule, Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2020. 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.

1. Navigator Program Standards - §155.210

We take this opportunity to point out to CMS that since 2016, funding for the Navigator program has been reduced by 84%.¹ This has led to a total reduction in funding for some states and entire geographic regions where there were no Navigators to provide services, including "Cleveland, Akron, Toledo and Youngstown in Ohio, Dallas, San Antonio and Austin in Texas, all of Michigan outside of the Detroit metro area."² These ongoing cuts directly affect people with disabilities as they generally have more considerations when comparing health insurance plans and ensuring that the plan they

¹ <https://www.kff.org/health-reform/issue-brief/data-note-further-reductions-in-navigator-funding-for-federal-marketplace-states/>

² <https://www.kff.org/health-reform/issue-brief/data-note-further-reductions-in-navigator-funding-for-federal-marketplace-states/>

select will cover their medical needs, something made more difficult without comprehensive consumer assistance programs.³

This is also true for the post-enrollment activities surrounding health literacy which includes understanding your plan and how to use it properly. People with disabilities are more likely to use their plan more and will require more assistance in understanding how to effectively utilize their plan. In addition, people with disabilities, like everyone else, experience changes in employment throughout the year and could be eligible for special enrollment periods or need to transition onto Medicaid, for which enrollment is year-round. In both instances, assistance from a navigator would be invaluable. While the proposed rules do not directly deal with the decreased navigator funding, this choice by the Administration to provide less money for a crucial important program continues to make it more difficult for people with disabilities to get the assistance they need. Given this, we would recommend that instead of making assistance with post-enrollment activities optional, the Administration restore full funding to the program to ensure that people, including people with disabilities, are getting they help they need.

In addition, we oppose CMS' proposed modification to the training requirements. We are concerned that in this change, any training to help navigators understand the needs of people with disabilities and other specialized populations would be insufficient. While the proposed rule will still require training in the needs of underserved and vulnerable populations, it is not clear that disability will be adequately addressed or, in fact, addressed at all.

2. Mid-Year Formulary Changes - §147.106, with other conforming amendments at § 146.152, § 148.122, § 156.122, and § 156.130

While we agree appreciate efforts to make generics available as soon as possible for individuals and support plans being allowed to add generic drugs to formularies mid-year, we oppose allowing issuers to also remove brand drugs from the formularies at the same time. It is important for CMS to recognize that brand name drugs are not identical to generics. While generic drugs may have the same active ingredients as the brand name drugs, they are not identical and universally substitutable. For people with chronic conditions such as HIV, epilepsy, and those who have disabilities, who rely of drugs as a matter of life and death, any changes to a treatment regime risk side effects, adverse reactions, and unnecessary and expensive additional health care services, such as emergency visits or hospitalizations. If individuals are going to transition it must

³ National Disability Navigator Resource Collaborative, Guide to Disability for Healthcare Insurance Marketplace Navigators (Jan. 2015), <https://nationaldisabilitynavigator.org/wp-content/uploads/Materials/>

be a carefully arranged plan and there must be flexibility for individuals who do not respond well to the generic to be able to obtain brand name drugs. Simply cutting off access to a functional drug mid-year of a plan also violates the consumer transparency that CMS acknowledges is so crucially important.

3. Essential Health Benefits

We appreciate CMS' caution to states about ensuring that benefit design not discriminate against people with disabilities. We remain concerned, as we were last year, that these additional options available to states to redefine their benchmark benefits coverage may create a "race to the bottom" in the scope of coverage. Rehabilitation and habilitation services and devices, mental health and substance use disorder services, prescription drugs, and the other EHBs are simply too important to allow States to substantially limit these benefits in redefining new EHB benchmark plans. These benefits must be available to individuals when they truly need them. Access to essential health benefits can save significant health care dollars in the long term and reduce the need for more intensive health care services later in life. CCD has significant concerns that the proposals CMS finalized last year will erode consumer protections and comprehensive coverage. The statutory mandate to cover these essential health benefits while ensuring that benefit design is non-discriminatory based on disability are clear and important guardrails that CMS should ensure are met.

In addition, while CCD understands that CMS will rely on states to monitor these areas, we believe that there is an ongoing federal role, which does not conflict with or impede a state in exercising its role, in regulating health insurance markets. This is particularly important in avoiding discrimination based on an individual's underlying medical condition and we urge CMS to take a more active enforcement role.

4. Premium Adjustment Percentage and Maximum Annual Limitation on Cost Sharing - § 156.130

We must disagree with CMS' assessment that "the premium trend is more stable," justifying a modification of the premium adjustment methodology. In 2019, insurers had to adjust premiums to reflect "the repeal of the individual mandate penalty [. . .] and the proliferation of short-term, limited duration (STLD) health plans" leading to premium increases of 6 percent.⁴ In addition, we cannot support the Administration's modified premium adjustment methodology. Analysis of the proposal suggests that the proposal

⁴ <https://www.kff.org/health-costs/issue-brief/tracking-2019-premium-changes-on-aca-exchanges/>

would increase costs for 7.3 million families and individuals on the exchanges.⁵ The impact this change would have on maximum out-of-pocket limits is particularly concerning for people with disabilities and chronic conditions, because they are more likely to reach that maximum and would be disproportionately impacted by this change. People with disabilities and chronic conditions will also be harmed by the impact this will have on the size of the risk pool in the exchanges: the Administration itself estimates 100,000 people each year will drop marketplace coverage and as the proposal itself admits, “could ultimately result in net premium increases for enrollees that remain in the individual market, both on and off the Exchanges, as healthier enrollees elect not to purchase Exchange coverage.”⁶ We urge CMS not to finalize this proposal and instead to revert to the prior methodology.

5. Application to Cost-Sharing Requirements and Annual and Lifetime Dollar Limitations - § 156.130

We strongly oppose the proposal to eliminate coverage of brand name drugs when both brand and generic drugs are available and to render such brand name drugs out of the Essential Health Benefits package. As discussed above, we share CMS’ concerns about “the cost of prescription drugs, and particularly brand drugs,” but passing these costs on to consumers with specialized health care needs is not the solution and we urge CMS not to finalize this proposal.

6. Automatic Re-Enrollment

People with disabilities know better than most how important it is to review their coverage options every year. We strongly encourage CMS to take steps to ensure that people have access to help in making these decisions, such as restoring drastically reduced Navigator funding (discussed above), and returning to a longer enrollment period, allowing for more time to select a plan. We would also encourage restoring the advertising and outreach and engagement efforts put into the open enrollment period. We believe these steps would be a better approach than eliminating automatic re-enrollment, which is likely to reduce the number of covered individuals and increase costs for all individuals. 1.8 million people auto-reenrolled at HealthCare.gov in 2019, just over 20 percent of the entire market.⁷ These individuals may be happy with their coverage or be unable to review options within the limited time and other responses, beyond ending auto-enrollment would be far more useful. Also, ending this automatic process carries a significant risk of destabilize the individual market by splitting the risk

⁵ <https://www.cbpp.org/sites/default/files/atoms/files/1-18-19health.pdf>

⁶ 84 Fed. Reg. 16, 287 (Jan. 24, 2019).

⁷ <https://www.cms.gov/newsroom/fact-sheets/final-weekly-enrollment-snapshot-2019-enrollment->

pool and dramatically increasing costs for people with higher care needs who must purchase insurance. We urge CMS to continue the use of automatic re-enrollment and utilize other tools to address eligibility errors, tax credit miscalculations, unrecoverable federal spending on the credits, and general consumer confusion.

6. Increased Consumer Transparency

We appreciate and agree with CMS' concern that there is insufficient transparency regarding consumer cost-sharing. Consumers face many challenges when shopping for health care, not only in understanding the financial responsibility with regards to coinsurance, but also with balance billing and reference prices and surprise out of network bills. It is practically impossible for a consumer to determine the cost of a service before a service has been rendered. In addition, the extent of coverage of certain services, such as rehabilitation and habilitation and behavioral health services, is remains opaque, as do drug formularies when consumers go to purchase of a qualified health plan. We strongly support CMS taking steps to increase transparency in the exchanges with regards to cost-sharing and coverage.

7. High-Deductible Health Plans and Health Savings Accounts

While supporting these transparency efforts, CCD urges CMS to not promote High-Deductible Health Plans (HDHPs) (in conjunction with or without Health Savings Accounts). In a recent survey of Americans' challenges with health care costs, 43 percent reported difficult affording their deductible.⁸ In addition, 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."⁹ Instead, enrollees use less health care across the board, including preventive or other necessary care.¹⁰ HDHPs also do not save money long term, instead provide at best short-term savings that disappear in the long-term and increase costs for low

period

⁸ <https://www.kff.org/health-costs/poll-finding/data-note-americans-challenges-with-health-care-costs/>

⁹ Teresa M Waters, et al., *Impact of High-Deductible Health Plans on Health Care Utilization and Costs*

Health Serv Res., 155–172 (2011). GAO, Federal Employees Health Benefits Program: First-Year Experience with High-Deductible Health Plans and Health Savings Accounts, GAO-06-271 (2006).

¹⁰ The Commonwealth Fund, Sara R. Collins et. al, *The Problem of Underinsurance and How Rising Deductibles Will Make It Worse: Findings from the Commonwealth Fund Biennial Health Insurance Survey, 2014 (2015)*, <https://www.commonwealthfund.org/publications/issue-briefs/2015/may/problem-underinsurance-and-how-rising-deductibles-will-make-it>; RAND, Rachel Effros, *Increase Cost-Participation by Employees (e.g., Through High-Deductible Health Plans)* (2009), https://www.rand.org/pubs/technical_reports/TR562z4.html.

income families. ¹¹ If CMS does decide to promote such plans, 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. In addition, it is important for CMS to make it clear that plans are most useful to people with high incomes and significant personal savings who will be interested in the tax savings. HDHPs may attract consumers with low premiums, but are often a route to financial ruin for anyone who acquires a disability or chronic conditions.

8. Silver Loading

CMS should continue to allow Silver Loading until Congress acts to resolve the underlying problem of cost-sharing reductions. CCD believes that cost-sharing is a blunt and largely ineffective tool that discriminatorily impacts and creates a barrier to care for people with disabilities, chronic health conditions, and other heightened health care costs. If CMS does consider reforms to Silver Loading, we urge CMS to focus on ensuring that cost-sharing for consumers remains low.

Thank you for the opportunity to comment. If you have any questions please contact Rachel Patterson (rpatterson@efa.org) or Bethany Lilly (bethanyl@bazelon.org), co-chairs of the CCD Health Task Force.

Sincerely,

The CCD Health Co-chairs:

Bethany Lilly, Bazelon Center for Mental Health Law

Dave Machledt, National Health Law Program

Rachel Patterson, Epilepsy Foundation

Peter Thomas, Brain Injury Association of America

Julie Ward, The Arc of the United States

¹¹ JAMA Intern Med. 2017 Mar 1;177(3):358-368. doi: 10.1001/jamainternmed.2016.8411. Diabetes Outpatient Care and Acute Complications Before and After High-Deductible Insurance Enrollment: A Natural Experiment for Translation in Diabetes (NEXT-D) Study. Wharam JF1, Zhang F1, Eggleston EM1, Lu CY1, Soumerai S1, Ross-Degnan D1. (finding “low-income and HSA-eligible HDHP members experienced major increases in emergency department visits for preventable acute diabetes complications”).

