



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

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

Dr. Ellen Montz, Deputy Administrator & Director  
Center for Consumer Information and  
Insurance Oversight  
Department of Health and Human Services

**Re: RIN 0938-AU65; CMS-9911-P  
Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters  
for 2023**

**Dear Administrator Brooks-LaSure and Director Montz:**

On behalf of the undersigned members of the Consortium for Citizens with Disabilities' (CCD) Health Task force, we submit comments on the Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2023 proposed rule (hereinafter NBPP 2023 Rule).<sup>1</sup> 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 free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance.

We appreciate the opportunity to comment on the NBPP 2023 proposed rule. But before addressing our substantive comments, we note that the compressed timeline – 22 days from publication in the federal register to the comment due date – puts enormous pressure on stakeholders. The short window has substantially limited our ability to provide meaningful, considered solutions to resolve the complex issues that some of these policy proposals address, particularly in how they might impact the diverse population of people with disabilities. We ask that in the future HHS leave at least 60 days for public comment to permit more solution-oriented comments.

Our substantive comments on different sections of the rule are as follows:

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<sup>1</sup> 87 Fed. Reg. 584. Centers for Medicare & Medicaid Services (CMS), *Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2023* (Jan. 5, 2022), <https://www.federalregister.gov/documents/2022/01/05/2021-28317/patient-protection-and-affordable-care-act-hhs-notice-of-benefit-and-payment-parameters-for-2023>.

## **Guaranteed Availability of Coverage: Past Due Premiums (§ 147.104)**

In the proposed rule, HHS revises its previous interpretation of the ACA's guaranteed issue provision which allowed insurers to refuse to cover persons who owe past due premiums until they satisfy arrearages. We strongly support revising this unlawful interpretation of the guaranteed availability provision. The statute is clear – an issuer “must accept every employer and individual in the State that applies for such coverage.”<sup>2</sup> As HHS now acknowledges, denying coverage because of past-due premiums is contrary to the ACA, and disproportionately hurts persons who are low income and others experiencing economic hardship. People with disabilities are more likely to experience economic hardship,<sup>3</sup> and also more likely to suffer poor health outcomes from delays in accessing needed care.<sup>4</sup> Especially given the ongoing and devastating impact of the COVID-19 pandemic, no one should lose or be denied health care due to prior debts.

Health insurance companies have other tools available to recoup unpaid premiums without denying enrollment. We strongly support revising HHS' interpretation of the ACA's guaranteed issue provision to allow individuals to enroll in coverage even if they have past-due premiums.

## **FFE and SBE-FP User Fee Rates for the 2023 Benefit Year (§ 156.50)**

We strongly support a robust user fee to allow HHS to undertake a series of needed activities. We are unsure if the proposed user fee amount will provide sufficient funding to do so as it is difficult to assess the user fee amount without seeing the budget assumption on which it is based and the full scope of anticipated spending on activities such as navigators, improvements to healthcare.gov, oversight, etc.

HHS anticipates that spending on consumer outreach and education, eligibility determinations, and enrollment processes will need to increase by \$140 million above the 2022 benefit year level. This is in part due to projected enrollment declines when the enhanced premiums of the American Rescue Plan Act expire. [Modeling](#) shows that investing in a robust marketing and outreach campaign increases Exchange enrollment,<sup>5</sup> which typically leads to a healthier risk mix and thus lowers health care premiums, which often more than fully offsets the added costs of user fees.<sup>6</sup>

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<sup>2</sup> 42 U.S.C. § 300gg–1(a).

<sup>3</sup> U.S. Bureau of Labor Statistics. *Persons with a Disability: Labor Force Characteristics Summary*. (Feb. 24, 2021). Available at: <https://www.bls.gov/news.release/disabl.nr0.htm>

<sup>4</sup> Centers for Medicare & Medicaid Services. *Improving Health Care for Adults with Disabilities: An Overview of Federal Data Sources*. (Dec. 2020). Available at: <https://www.cms.gov/files/document/federaldatadisability508.pdf>

<sup>5</sup> Seervai, S. *Cuts to the ACA's Outreach Budget Will Make It Harder for People to Enroll*. Commonwealth Fund. (Oct. 11, 2017). Available at: <https://www.commonwealthfund.org/publications/other-publication/2017/oct/cuts-acas-outreach-budget-will-make-it-harder-people-enroll>

<sup>6</sup> Lee, P. V., Pegany, V., Scullary, J., & Stevens, C. *Marketing Matters: Lessons From California to Promote Stability and Lower Costs in National and State Individual Insurance Markets*. Covered California. (Sept. 2017). Available at: [https://hbex.coveredca.com/data-research/library/CoveredCA\\_Marketing\\_Matters\\_9-17.pdf](https://hbex.coveredca.com/data-research/library/CoveredCA_Marketing_Matters_9-17.pdf).

HHS should enable increased marketing and outreach efforts needed to effectively enroll consumers in the FFEs and SBE-FPs in 2023, even if this means a slight increase in the user fee rates to do so. We add the important caveat that additional funding for outreach must include targeted approaches to reduce access barriers and increase enrollment accessibility for people with disabilities, including plain language outreach, creating materials accessible for people with visual disabilities, and ensuring that navigator web-sites and hot lines are fully accessible for the range of people with disabilities and people with limited English proficiency.

Further, HHS proposes new requirements on agents, brokers and web-brokers to ensure the accuracy of information they provide and protect individuals. HHS will need sufficient funding and resources to ensure effective oversight of these new provisions that the user fee would support. This includes oversight to ensure that brokers and web-brokers also provide the required accommodations to make their services accessible.

#### **State Selection of EHB-Benchmark Plan for Plan Years Beginning on or after January 1, 2020 (§ 156.111)**

HHS proposes to establish an evergreen deadline for states to submit revisions to their EHB benchmark selections. Instead of specifying the deadline in each NBPP, states would need to submit their new benchmark selections by the first Wednesday in May that is 2 years before the effective date of the new EHB benchmark plan. We support this proposal. We urge HHS to further strengthen and expand the transparency and public comment process for EHB benchmark selection to ensure that stakeholders and other interested parties have ample opportunity to provide meaningful input.

#### **Provision of EHB (§ 156.115)**

HHS proposes to eliminate the provision allowing issuers to substitute benefits between EHB categories. We strongly support this proposal, and have long been concerned that substitution between and within EHB categories could lead to adverse selection by allowing insurers to discourage enrollment by persons with significant health needs. HHS rightly recognizes the potential harm to consumers with chronic illness and disabilities if insurance companies substitute benefits between EHB categories.

For example, the category of “rehabilitative and habilitative services and devices” was included in the ACA as an essential health benefit, one of ten essential categories of benefits that must be covered by ACA health plans. It is noteworthy that Congress chose to include a separate EHB category for rehabilitative and habilitative services and devices to specifically list in the statute in recognition of the important role the benefit plays in helping ensure that adults and children maximize their health, function, ability to live independently, and participation in society. Subsequent rule-making has created, for the first time, a federal definition of habilitative

services and devices.<sup>7</sup> The federal coverage standard for habilitation benefits has been responsible for a dramatic increase in access to these important benefits, which often were not covered by private insurance prior to the ACA. To protect access to these and other important services, we urge HHS to ban substitution not only between categories, but within EHB categories.

Furthermore, CMS should collect and make publicly available data on the services provided in these benefits identified by the new claims modifiers to better ascertain the availability of these services and any potential barriers to access or imbalances between coverage of rehabilitation and habilitation services. As clarified in the 2016 NBPP final rule, plans cannot impose any limits on habilitation that are less favorable than those imposed on rehabilitation. Unfortunately, a lack of robust data on the provision of these benefits makes it difficult to confirm to what extent this requirement is being followed.

Better data collection, made available to stakeholders and the public, will also illuminate whether future policy changes must be made to protect access to these services, including to ensure that the requirement for separate limits on rehabilitation and habilitation services is being followed.

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

The proposed rule clarifies insurers' obligation to comply with EHB nondiscrimination requirements and provides a regulatory framework to evaluate plan benefit design and implementation based upon clinical guidelines and evidence. We strongly support this proposal and the examples of presumptively discriminatory benefit design that HHS provides.

Insurance companies have used many features of health plan benefits and delivery to unlawfully deny needed coverage or discourage people with significant health needs from enrolling in their plans. These include exclusions, high cost sharing, limited formularies, visit limits, narrowed provider networks, prior authorization and other utilization management that are arbitrary and not clinically-based or appropriate.

We welcome and support HHS' framework to address and end discriminatory plan benefit design and delivery. HHS takes the right approach, establishing that nondiscriminatory benefit design must be clinically based, 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.

While we support a robust evidence-based standard to limit discriminatory benefit design, we also urge CMS to ensure that, in advancing the goals of nondiscrimination, the clinical evidence used is not biased or discriminatory itself. Historically, much racist and eugenicist scholarship

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<sup>7</sup> 80 Fed. Reg. 10811-12 (Feb. 27, 2015).

has been published in medical journals, and the medical research field is not yet free of racism or anti-disability bias. Prominent bioethicists still question whether older people, people with disabilities, and people with chronic health conditions are worth treating. Many health economists continue to use the quality-adjusted life year (QALY), which people with disabilities consider discriminatory and the National Council on Disability has recommended federal and state governments ban from their programs. We urge CMS, when reviewing the clinical evidence used to defend plan design, to ensure that the evidence itself is not discriminatory in nature. This would include, but is not limited to, the use of the QALY.

We also urge that CMS find ways to maintain access to services and treatments that may be beneficial but are not conducive to conventional methodologies for developing a clinical evidence-base. For example, some people with disabilities have conditions so rare that a clinical trial is not feasible.

### *Copay Accumulators*

Copay assistance is a lifeline, allowing many individuals to access critical, life-saving medications. Over the years, insurers have shifted costs to enrollees, with higher deductibles and increasing coinsurance. Many people with chronic health conditions, especially those who rely on specialty medications, have sought financial help to cover the increasing cost of prescription drugs. While many individuals will never hit an out-of-pocket limit of \$9,100 (the proposed amount for 2023), people with certain chronic health conditions may regularly reach these limits, often in the first few months of the year. Copay assistance is often the only way they can afford the medication they need, even if they have insurance.

The NPRM seeks to refine Section § 156.125 and directly addresses the issue of discriminatory benefit design through adverse cost sharing tiering schemes.<sup>8</sup> While we support CMS' intention to ensure that benefit design reflects clinical evidence rather than an effort to discriminate against people with high health care needs, we also strongly recommend CMS include language in this section also prohibiting use of copay accumulator adjustment policies, which discriminate against people living with chronic illness.

Extensive research documents that high out-of-pocket costs cause people to abandon, or fail to initiate, prescription medications, particularly for lower income individuals.<sup>9</sup> For patients with a serious condition like HIV, multiple sclerosis, cancer, epilepsy, or hemophilia, delaying or forgoing treatment may result in severe deterioration of their condition, permanent disability or even death.

Some have expressed concern that manufacturer copay assistance incentivizes physicians to

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<sup>8</sup> 87 Fed. Reg. 667.

<sup>9</sup> Michael T. Eaddy et al., *How Patient Cost-Sharing Trends Affect Adherence and Outcomes: A Literature Review*, 37 *Pharmacy & Therapeutics* 45 (2012); Dana P. Goldman, Geoffrey F. Joyce & Yuhui Zheng, *Prescription Drug Cost Sharing: Associations with Medication and Medical Utilization and Spending and Health*, 298 *JAMA* 61 (2007).

prescribe more expensive drugs. This is not the case in many conditions and for people with disabilities. For example, epilepsy medications are not interchangeable and treatment of epilepsy is highly individualized. Selection of the appropriate medication to prevent seizures is determined by a number of variables, including type of seizure, seizure frequency, age, gender, and other health conditions. This careful selection will increase if a person has co-occurring conditions.

### **Medical Loss Ratio (§ 158.150)**

Insurers that have failed to spend at least the required amount of premium revenue on clinical services versus administrative expenses must rebate enrollees. In 2020 and 2021, these rebates have exceeded \$2 billion. CMS identifies egregious examples of insurers using various tactics to avoid paying rebates owed to consumers. For example, insurers have attributed indirect expenses to quality improvement activities (QIA) – including the purchase of artwork and travel and entertainment expenses – to inflate health spending and deprive consumers of rebates. Limiting the definition of a quality improvement activity to include only direct expenses related to clear quality or clinical standards is both appropriate and necessary.

We also encourage HHS to reconsider the standards a wellness program must meet to qualify as a QIA. The proposed rule expresses concern that some issuers incorrectly classify profits they make for providing wellness incentives to enrollees. We are further concerned that issuers may classify as QIAs many programs and activities that do not actually promote or increase wellness and health. Wellness programs have at best a mixed track record in improving wellness, and such programs may actually pose risks to people with lower incomes or who are in poor health. We urge HHS to take steps to prevent issuers from benefiting under MLR rules by using purported wellness activities that lack an evidentiary basis for positive health outcomes.

### **Standardized Plan Options (§ 156.201)**

We strongly support HHS's proposal to require issuers to offer at least one standardized plan at every product network type, metal level, and in every service area where the issuer also offers non-standardized plans. Plan standardization will enable consumers to more easily compare plans by standardizing cost-sharing requirements, thereby allowing individuals to focus on other factors that are more crucial to consumers' health, such as premiums, provider network, and quality of services. In addition, standardization serves improves affordability in the Marketplace by ensuring that consumers always have access to at least one plan that exempts certain important services from deductibles. We also strongly support requiring standardized plans to use fixed copays instead of coinsurance, which disproportionately burdens persons with chronic illness and disabilities. By improving affordability to basic services that underserved populations typically lack access to, the proposal will also help address health disparities in the long run. The effectiveness of standardization in improving access and affordability is evident by the experience of the nine states and the District of Columbia that have already adopted standardization in their state-run exchanges. We are pleased that the

federal government is now extending the policy to federally facilitated exchanges and state-based exchanges that use the federal platform.

However, we urge HHS to also address the high deductibles in some of the standardized plans. We are especially concerned with the \$9,100 deductible in the Bronze standardized option. According to research previously cited by the Department in other rulemaking, nearly 4 in 10 adults would have difficulty paying for an emergency expense costing \$400.<sup>10</sup> People in this circumstance are the most likely to choose a Bronze option based on premium cost. With the potential to face \$9,100 in charges, they are functionally uninsured and may not seek needed care due to cost.

### **Network Adequacy (§ 156.230)**

We commend HHS for revisiting these regulations to add new provisions aimed at ensuring that QHP enrollees have meaningful access to all essential health benefits. We support HHS's proposal to evaluate networks of QHPs and potential QHPs in the FFE prior to their certification, and post-certification review of compliance with appointment wait time standards in response to random sampling or complaints. We urge HHS to closely scrutinize both the standards and review process before allowing states that perform plan management functions to perform their own reviews of network adequacy to ensure that both are indeed at least as stringent as the established federal standards, and that networks are reviewed before QHPs are certified.

Similarly, we believe that in future rulemaking, HHS should consider using the FFE standards as a floor for State-based Exchanges. This would allow states to perform their own reviews of network adequacy as long as both the state standards and review process are at least as stringent as the established federal standards and process. We emphasize that network adequacy reviews, whether performed by HHS or by states, must include direct testing, such as secret shopper surveys of provider directories, or data systems that capture appointment details, and that these reviews should specifically evaluate provider accessibility and availability for people with disabilities.

#### *Time and Distance Standards*

We strongly support HHS's proposal to codify provider and facility types that will be subject to time and distance standards. Placing this information in the regulation is an important step toward ensuring that QHP enrollees have meaningful access to essential health benefits.

We commend HHS for including "Outpatient Clinical Behavioral Health" as a provider type subject to time and distance standards, and for making clear that this provider type can include licensed, accredited, and certified professionals. We suggest that HHS split this category into

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<sup>10</sup> Board of Governors of the Federal Reserve System, Report on the Economic Well-Being of U.S. Households in 2018 (May 2019), available at: <https://www.federalreserve.gov/publications/2019-economic-well-being-of-ushouseholds-in-2018-dealing-with-unexpected-expenses.htm>.

two groups, one for “Outpatient Clinical Mental Health” providers and another for “Outpatient Clinical Substance Use Disorder” providers. Putting all behavioral health providers into one category could cover up shortages of either mental health or substance use disorder service providers, and most behavioral health providers do not offer both mental health and substance use disorder services.

We also encourage CMS to include audiology in this list as well. Audiologists play a critical role in habilitation for individuals with hearing and related disorders, working individually and/or with other specialties to enhance their overall health status, independence, and quality of life. Also, several settings where habilitation and rehabilitation services are frequently provided are not included in the proposed facility specialty list for the time and distance standards. In particular, inpatient rehabilitation facilities (IRFs), comprehensive outpatient rehabilitation facilities (CORFs), and long-term care hospitals (LTCHs) are omitted, though skilled nursing facilities (SNFs) are included. We encourage CMS to add these facilities to the list to ensure that QHP enrollees have adequate access to these critical settings of care.

Furthermore, we note that time and distance standards should not always be used as the sole measure of network breadth, given shortages of some types of providers and the ongoing regionalization of some specialty care. For example, those standards do not appropriately account for children with medically complex conditions or other special health care needs who must travel long distances to receive care, including habilitative services, at children’s hospitals that serve large regions. One study<sup>11</sup> found that nearly half of pediatric specialty hospitalizations took place outside of adult-focused distance standards. Similarly, an analysis<sup>12</sup> by the Children’s Hospital Association 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.

We also support HHS’s proposal to measure appointment wait times. We appreciate that HHS has identified a “short list of critical service categories” to which appointment wait times should apply. We recommend that HHS add Urgent Care to this list. The experience of people during the COVID-19 pandemic has highlighted the crucial role that Urgent Care centers provide in delivering care to people who need it quickly, but whose condition does not rise to the level of an emergency. They also help make diagnostic testing and screening services available when primary care provider offices are not open.

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<sup>11</sup> Colvin, J., et. al. *Hypothetical Network Adequacy Schemes for Children Fail to Ensure Patients’ Access to In-Network Children’s Hospital*, Health Affairs 37, No. 6 (June 2018): 873-880. Doi: 10.1377/hlthaff.2017.1339,

<sup>12</sup> *An Examination of Certain Network Adequacy Measures and their Potential Impact on Children’s Access to a Children’s Hospital*, Children’s Hospital Association, December 2014. Available at:

[https://www.childrenshospitals.org/-/media/Files/CHA/Main/Issues\\_and\\_Advocacy/Key\\_Issues/Exchanges\\_and\\_Private\\_Coverage/Issue-Briefs-and-Reports/Capacity\\_of\\_Childrens\\_Hospitals\\_Dec2014.pdf](https://www.childrenshospitals.org/-/media/Files/CHA/Main/Issues_and_Advocacy/Key_Issues/Exchanges_and_Private_Coverage/Issue-Briefs-and-Reports/Capacity_of_Childrens_Hospitals_Dec2014.pdf)



We strongly support HHS's proposal that plans that use tiered networks may only count providers contracted within the network tier that results in the lowest cost-sharing obligation toward satisfying the network adequacy requirements.

In addition, we urge HHS to clarify QHPs' obligations to their enrollees when they are unable to meet time and distance or appointment wait-time standards. Even the most robust networks will occasionally fail to accommodate extremely rare and specialized services, and may experience times when providers are temporarily unavailable, which can require enrollees to travel further and wait longer to access care. For example, many health care providers have recently experienced temporary staff shortages due to COVID infections. We urge HHS to make clear that in these situations, QHPs must hold their enrollees financially harmless for seeking care from out-of-network or higher tier providers, and must clearly explain the process for seeking an exception in beneficiary materials and on their website.

We support HHS's proposal to require all issuers seeking certification of plans to be offered as QHPs through the FFE to submit information about whether network providers offer telehealth services. Over the last few years we have learned a lot about the use of telehealth, and gathering this information will help inform future rulemaking about the role telehealth plays in comprising a network sufficient to deliver covered services to enrollees without limiting in-person access. We believe that more information is needed before rulemaking in this area would be prudent, and thus strongly support the proposal to collect this information.

We also support HHS's proposal to raise the Essential Community Provider (ECP) participation standard to 35 percent. Indeed, we believe HHS should strengthen this standard by requiring QHPs to satisfy this threshold for each category of ECP rather than for all ECPs combined. This would ensure that QHP enrollees have adequate access to all of the important types of ECPs, which range from Ryan White providers to FQHCs. As above, we believe that plans with tiered networks may only count ECPs contracted within the network tier that results in the lowest cost-sharing obligation toward satisfying the 35 percent threshold.

#### **Quality Standards: Quality Improvement Strategy (§ 156.1130)**

The proposed rule would require all QHPs with at least two consecutive years in a market to include in their quality improvement strategies (QIS) at least one payment structure that provides financial incentives for activities aimed at reducing health and health care disparities. We support this policy change as an initial step, but ask CMS to require more public transparency and accountability about the process of selecting, implementing, evaluating, and reporting the outcomes of QIS interventions.

The proposed QIS policy does tie effective performance on reducing health and health care inequities to financial reward, but it lacks two key elements. First, QHPs should have to seek input from enrollees and stakeholders who represent underserved communities in the plan service area to guide their QIS activity selection and shape which activities related to health or

health care inequities they prioritize. Second, more public accountability is necessary to reassure the public that issuers (and CMS) take these initiatives seriously.

In Medicaid managed care, plans must undertake Performance Improvement Projects (PIPs) that could be useful to inform the QIS policy in this area. External Quality Review mandates annual evaluation and public reporting of PIP outcomes, and the Quality Strategy process offers stakeholders a forum to provide input on state quality priorities.

With this degree of public transparency in Medicaid, we have found that many PIPs are poorly organized, fail to create adequate baseline data, and/or have little positive impact on improving outcomes. For example, Minnesota required Medicaid plans to conduct and report on three-year PIP to improve racial and ethnic disparities in depression management.<sup>13</sup> The results were disappointing. Of eight participating plans, two showed markedly worse disparities after three years, three more showed little change in overall rates or disparities, two did not disaggregate their data by race, and the last two did not report or had too small a data sample.<sup>14</sup> Only one of eight plans reported an increase in depression management that met its stated goals, and that plan did not disaggregate the outcome by race.<sup>15</sup>

We believe that Medicaid PIPs might be more successful if they were more directly tied to financial incentives, as would be included in the QHP requirement proposed here. However, without substantial public accountability improvements, we are skeptical that QIS activities will demonstrably move the bar on health equity or other priorities related to care quality.

We recommend that, CMS add these public accountability improvements to the regulation at § 156.1130, in addition to the proposed requirement that plans develop at least one payment structure aimed at reducing health inequity in their quality improvement strategy.

### **Solicitation of Comments Regarding Health Equity, Climate Health, and Qualified Health Plans**

We strongly support requirements for QHPs to collect information on each enrollee's race, ethnicity, gender, sexual orientation, primary language and disabilities. Asking enrollees to provide this information is a necessary first step to track persistent health inequities and to reveal those that are yet unidentified. HHS – for all of its programs and not solely marketplaces – should review expert recommendations and research on demographic data collection and set standards for the language QHPs use to ask individuals to share their demographic information. Recommendations on how to do this successfully already exist from the [Institute of Medicine](#),

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<sup>13</sup> Island Peer Review Org. ["IPRO"], *Minnesota EQR Technical Report 2017*, 15 (Apr. 2019), <https://edocs.dhs.state.mn.us/lfserver/Public/DHS-6888E-ENG>. Blue Plus showed an increasing disparity of 8 percentage points over 3 years. Hennepin Health showed an increase of 14.3 percentage points over the same period.

<sup>14</sup> Id. at 18, 31, 43, 55, 66, 75, and 89.

<sup>15</sup> Id. at 89.

[the Williams Institute at UCLA](#),<sup>16</sup> and forthcoming from the [National Academies of Sciences, Engineering, and Medicine](#). They draw on both studies and stakeholder input. The ultimate purpose of collecting voluntary demographic information from enrollees is to advance health equity. As such, HHS should also set expectations for QHPs to engage in systematic review of enrollee data, ensure they are using best practices to collect that data, and take actions to correct disparities that become apparent through their review.

We also recommend that HHS set an example by improving data collection in its own programs and activities, such as collecting comprehensive demographic data in HealthCare.gov and requiring SBEs to do the same. This will not likely preclude the need for QHPs to also collect this data, particularly because some individuals will be more confident providing demographic data to a plan or provider (who shares it with a QHP) as opposed to a government agency to enroll in a program. It *will* demonstrate HHS' own commitment to collecting and utilizing demographic data to address health disparities and improve health equity.

Additionally, HHS requested comment on whether QHPs should be required to obtain NCQA's Health Equity Accreditation. We support this requirement. HEA's standard for accreditation captures the importance of data collection and affirmative steps that QHPs can take to use health disparity data to improve health equity. However, the HEA lacks specific standards that address people with disabilities. We recommend that HHS work with NCQA and stakeholders from the disability community to add standards that promote equity for disabled enrollees, including comprehensive data collection. HHS should retain responsibility for oversight of QHP accreditation, and materials provided to NCQA by QHPs, such as scorecards and evaluations, should be publicly available.

## **Conclusion**

Thank you for the opportunity to comment on this important issue. If you have further questions, please contact David Machledt ([machledt@healthlaw.org](mailto:machledt@healthlaw.org)).

Respectfully Submitted,

American Association on Health and Disability  
American Music Therapy Association  
American Speech-Language-Hearing Association  
Autistic Self Advocacy Network  
The Arc of the United States  
Bazelon Center for Mental Health Law  
Brain Injury Association of America  
Center for Medicare Advocacy  
Disability Rights Education and Defense Fund (DREDF)

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<sup>16</sup> <https://williamsinstitute.law.ucla.edu/publications/data-collection-sogi/>;  
<https://williamsinstitute.law.ucla.edu/publications/smart-so-survey/>;  
<https://williamsinstitute.law.ucla.edu/publications/geniuss-trans-pop-based-survey/>

Epilepsy Foundation

Justice in Aging

National Association of State Head Injury Administrators

National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)

National Council on Independent Living

National Health Law Program

National Multiple Sclerosis Society