



January 27, 2022

via Online Portal (www.regulations.gov)

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 and 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:

The Disability Rights Education and Defense Fund (DREDF) and the Judge David L. Bazelon Center for Mental Health Law (Bazelon) appreciate the opportunity to comment on the Centers for Medicare & Medicaid Services (CMS) proposed rule, Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2023 (hereinafter 2023 NBPP Rule). DREDF is a national cross-disability law and policy center that protects and advances the civil and human rights of people with disabilities through legal advocacy, training, education, and development of legislation and public policy. We are committed to increasing accessible and equally effective healthcare for people with disabilities and eliminating persistent health disparities that affect the length and quality of their lives. Bazelon is a national non-profit legal advocacy organization that promotes equal opportunity for individuals with mental disabilities in all aspects of life, including health care, community living, housing, education, employment, voting, and other areas.

I. Introduction

Our comments on the provisions of the NBPP 2023 Rule do not cover the full range of topics raised in the rule but are intended to address key areas of particular importance to people with disabilities. We especially want to highlight the nondiscriminatory benefit design proposals—including the sexual orientation and gender identity non-discrimination sections and presumptively discriminatory examples of benefit design

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below. DREDF and Bazelon have long called for more regulatory guidance and policy on the multiple forms of discriminatory benefit design prohibited by the Affordable Care Act (ACA) in light of the limited recourse that US courts have historically given plaintiffs with disabilities when health insurance coverage fails to include medically necessary services and treatments. We similarly draw attention to the ways in which Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex (LGBTQI+) individuals with disabilities are highly vulnerable when they experience healthcare discrimination because of their sexual orientation or gender identity. The National Council on Disability in a major report on The National Council on Disability in a major report on The Current State of Heath Care for People with Disabilities found that people with disabilities use healthcare services at a significantly higher rate, t end to be in poorer health, and experience a higher prevalence of secondary conditions. This leaves individuals in whom disability and LGBTQ+ intersect at greater risk when they encounter multiple sources of healthcare barriers. And finally, our comments on Medical-Loss Ratios (MLRs) are intended to encourage the inclusion of people with disabilities in the measure for achieving more equitable access to healthcare.

DREDF and Bazelon strongly supports many changes and additions proposed in the 2023 NBPP Rule to support people with disabilities—including those with mental disabilities, multiple disabilities, and intersectional identities—so that they may attain equal access to effective and affordable health insurance for the healthcare services they need to live full and productive lives in the community.

II. Nondiscrimination on the Basis of Sexual Orientation and Gender Identity (Part 147) (§§ 147.104(e), 155.120(c), 155.220(j), 156.125(b), 156.200(e), and 156.1230(b))

DREDF and Bazelon strongly support the proposed rule's provisions on prohibiting discrimination based on sexual orientation and gender identity among health exchanges, insurers, agents and brokers. An analysis of a 2017 national survey of Discrimination in the United States: Experiences of lesbian, gay, bisexual, transgender, and queer Americans found that 16% of LGBTQ adults experienced discrimination in a healthcare setting and 18% of LGBQ adults (and 22% of transgender adults) reported avoiding healthcare due to anticipated discrimination. The survey also found that negative experiences were more prevalent among LGBTQ persons who also belonged to non-white racial/ethnic groups. Another survey found that 29% of transgender people faced outright refusal of health because of their gender identity.

Transgender persons with disabilities bear a compounded burden from discrimination as documented in DREDF's research on Health Disparities at the Intersection of Disability and Gender Identity, which highlight how the largest survey of transgender persons in the US to date found that "39% of the nearly 28,000 transgender respondents had one or multiple disabilities, as compared with 15% of the general population." In another article exploring The Intersection Between Disability and LGBT Discrimination and Marginalization, the author notes how reported barriers in healthcare to LGBTQ people are particularly concerning because "people with disabilities likely

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need healthcare more than others," and also because of the greater incidence of reported disability among the LGBTQ population. Further, the "prevalence of mental health disabilities in the LGBTQ+ community makes the community particularly vulnerable to harmful mental health policy proposals." LGBTQ adults are twice as likely to experience mental illness and 2.5 times more likely to experience depression and anxiety. Individuals who identify as transgender are almost four times as likely to have a mental health disorder in comparison to those who identify as cisgender.

HHS' current limited recognition of healthcare discrimination on the basis of sexual orientation and gender identity has consigned LGBTQ persons with disabilities to receiving "second best" medical care by leaving them with few tools to address the longstanding and multiple barriers to achieving and maintaining good health. When insurers use transgender-specific exclusions to deny coverage for medically necessary treatment, including but not limited to gender-affirming treatment, or fail to support the rights of same-sex couples to receive reproductive counselling and services, they add to the burden of discrimination, stigma, and trauma endured by LGBTQ persons with disabilities. This proposed rule is a vital first step towards eliminating this life-threatening form of discrimination.

The proposed amendment is also within HHS' authority and furthers the ACA's clear intent of improving access to health coverage and medically necessary services. treatments, and devices. Provisions of the ACA indicate Congress's intent to ensure that regulations enacted under the ACA would not enact unreasonable barriers to obtaining appropriate medical care nor impede timely access to care (Pub. L. No. 111-148, sec. 18144 [Section 1554 of the ACA]). But overlooking the well-documented history of discrimination in healthcare on the basis of sexual orientation and gender identity leads to delayed and foregone healthcare, including behavioral healthcare, among LGBTQ persons with disabilities. Moreover, Section 1557 of the ACA is a broad marker of how much the law recognized that discrimination in all aspects of insurance can be an impediment to the receipt of needed healthcare. We recognize that the implementing regulations for Section 1557 are forthcoming and welcome the opportunity to separately comment on those provisions when they are published, but HHS can still take action as an agency to extend the same protections that are available to others to LGBTQ persons who experience discriminatory barriers to equally effective healthcare. To not do so would not only be an ethical failing, but also a failure to effectuate the intended purposes of the ACA.

¹ https://www.samhsa.gov/data/sites/default/files/NSDUH-SexualOrientation-2015/NSDUH-SexualOrientation-2015/NSDUH-SexualOrientation-2015.htm;

https://www.psychiatry.org/psychiatrists/cultural-competency/education/lgbtq-patientshttps://pdas.samhsa.gov/#/survey/N-MHSS-2019-DS0001

² https://www.samhsa.gov/data/sites/default/files/NSDUH-SexualOrientation-2015/NSDUH-SexualOrientation-2015/NSDUH-SexualOrientation-2015.htm;

III. Federally Certified Risk Adjustment Methodology (§ 153.320)

The proposed rule would make several changes to the individual and small group market risk adjustment program. One of those proposed changes is to adopt a "two-stage" method for estimating the parameters of CMS' risk score models. CMS indicates that the intended effect of this change is to reduce how much insurers that attract lower-risk enrollees pay into risk adjustment (which, in turn, would reduce how much insurers that attract higher-risk enrollees receive from risk adjustment).

Because higher-risk enrollees are more likely to select higher-quality plans (e.g., plans with broader provider networks, larger formularies, or less onerous utilization controls), we are concerned that this proposal would increase the premiums of higher-quality plans. This would make it harder for consumers to afford these plans and increase premium burdens for consumers with greater health care needs.

We are also concerned that this proposal would create incentives for insurers to reduce the quality of the coverage they offer, both in general and for high-risk enrollees in particular. Those types of insurer responses would exacerbate the problems that the stronger network adequacy and nondiscrimination standards that are also included in the proposed rule aim to address. We are not in favor of this proposal.

IV. Ability of States to Permit Agents and Brokers and Web-Brokers to Assist Qualified Individuals, Qualified Employers or Qualified Employees Enrolling in QHPs (§ 155.220)

We also support the proposal to expand the types of entities who may assist qualified individuals, qualified employers, or qualified employees enrolling in QHPs, provided there are proper safeguards. Previously, agents, brokers, and web-brokers have not been required (unlike navigators funded by marketplaces) to provide accurate and unbiased information to individuals. This proposal would help remedy that issue.

Currently, web brokers in the federally-facilitated marketplace (FFM) are required to display all plans available to a consumer in their rating area. Web brokers display the plans they support enrollment in—generally, those that pay commissions – but display only the insurer, plan name and type, and metal tier for those they do not sell, along with a disclaimer that more information can be found at HealthCare.gov. The lack of additional comparative information, such as the premium and deductible, hinders consumers' ability to make meaningful comparisons between plans. The proposed rule specifies additional plan elements that must be displayed when a web broker facilitates enrollment in a plan and, for web brokers that do not, changes the disclaimer to specify that *enrollment*, not just more information, is available at HealthCare.gov. This change is a positive step but does not go far enough to allow consumers to compare plans. For example, CMS could direct web brokers to display unsupported plans in their cost comparison tools instead of segregating them at the bottom of the page. We support

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other important provisions that are included in the proposed rule to improve transparency for consumers. The rule would prohibit advertising or other fee-based preferential displays of plans and require web brokers to explain their rationale and methodology for recommending a plan to a consumer.

The proposed rule would also tighten the standards of conduct for agents, brokers, and web brokers to further protect consumers and give CMS additional grounds for enforcement. First, the rule prohibits discrimination based on sexual orientation and gender identity (see additional comments on the nondiscrimination provisions herein). Second, the rule spells out more specific guidelines for what it means to submit accurate client information by making it a violation to submit information such as their own business's email, phone number, or address instead of a client's information. Certain malfeasance, such as using email addresses consumers can't access or submitting inaccurate income, would also violate the rules. Third, automated interactions that lead to unauthorized enrollment or changes to enrollment would be prohibited, information used for identity proofing would need to belong to the client, and special enrollment period (SEP) eligibility would need to be ascertained individually with the consumer informed of the reason for their SEP. While these practices are already prohibited, they persist. We urge CMS to dedicate the funding necessary to support monitoring and enforcing compliance with these and all agent, broker, and web broker standards, including mechanisms to make the comparison of plans more accessible for people with disabilities.

V. Annual Eligibility Determination (§ 155.335)

We appreciate HHS' request for comments on incorporating consumer costs into redetermination and reenrollment procedures. We recommend changing two policies that affect enrollees who are being renewed without making an affirmative selection of plan.

The first current policy keeps the enrollee in their past plan if it remains available during the new plan year, even if a change in market conditions has significantly raised the old plan's cost to the consumer. We recommend HHS change this policy so that when the enrollee is certain to be better off in a different plan, the enrollee is shifted to that plan, unless they opt out. The exchange would need to provide notice of the change and reasons for the change—including the same access to community-based behavioral health providers, and reasonable opportunities, both before and after the shift, for the consumer to return to their former plan or drop coverage altogether. We do caution, however, that people with disabilities may choose specific plans, for example because of their need for very particular types of care or their reliance upon a longtime key provider with whom they have established trust and a history of effective medical interventions. Any notice provided under this provision should explain, in plain language, the reason for the change of plan and all potential negative repercussions

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because of the shift (including, for example, any reductions of coverage of any services and devices or anticipated changes in provider access).

This limited exception to plan continuity would apply only when:

- both plans are sponsored by the same carrier, are included in the same product, have the same provider network—including to community-based behavioral health providers, the same prescription drug formulary, and substantially the same coverage of rehabilitative and habilitative services and devices;
- the new plan neither has higher net premiums or lower actuarial value (AV) than the previous plan; and
- the new plan has lower net premiums, significantly higher AV, or both, compared to the former plan.

Researchers found that in Covered California's 2018 market, fully 30% of households whose coverage was automatically renewed were certain to be better off in a different plan. On average, families were charged an extra \$466 a year in annual premiums, as a result of remaining with a plan that no longer served their interests.³

The second current policy provides that if the former plan is no longer available, the enrollee is shifted to the most similar available exchange plan offered by the same carrier, even if consumer costs are far higher with the new plan. This defaultassignment rule assumes that the most important factor in most consumers' plan choice involves the carrier and provider networks. Such factors certainly matter to many consumers. However, with consumers who do not shop at all during the open enrollment period (OEP), the vast majority care more about cost than carrier or provider network. Accordingly, we recommend that CMS prioritize in the default reenrollment hierarchy that when the consumer's former plan is no longer offered, keeping the consumer's net premium cost and approximate AV at levels as close as possible to (and no higher than) those in the member's plan the previous year. The notice informing the consumer of the change in plan should let the consumer opt out of the change by selecting a different plan, chosen based on the current reenrollment hierarchy, or by terminating coverage altogether. As noted above, this notice shall also state the reason for the change of plan and all potential negative repercussions of the shift (including, for example, any reductions of coverage of any services and devices.

VI. State Selection of Essential Health Benefit (EHB)-Benchmark Plan for Plan Years Beginning on or after January 1, 2020 (§ 156.111)

We support the agency's proposal to set an "evergreen" deadline for states to submit revisions to their EHB benchmark selections. Requiring states to submit any new benchmark selections by the first Wednesday in May that is 2 years before the

³ https://www.milbank.org/quarterly/articles/when-all-that-glitters-is-gold-dominated-plan-choice-on-covered-california-for-the-2018-plan-year/.

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proposed effective date of a new EHB benchmark plan should give the state and HHS sufficient time to solicit comments and opinions from the public and all interested parties who will be affected by the change while also enabling issuers to determine how they will meet the new EHB while also giving due regard to non-discrimination and actuarial considerations. DREDF and Bazelon recommend that, in light of such a clear deadline, HHS take the opportunity to further detail and strengthen the public comment process to ensure that consumers with disabilities and disability advocates will not be surprised by EHB changes and encouraged to explain how the proposed change will affect their healthcare needs. Many consumers with disabilities depend on the availability of benchmark EHB and will require any changes to be transparently considered, responsive to the possibility of unintended consequences, and transparently explained by the state and by issuers in plain language once the change is made.

VII. Provision of EHB (§ 156.115)

DREDF and Bazelon support HHS' proposal to eliminate the current provision allowing issuers to substitute benefits between EHB categories. When the provision was enacted in 2019, its purported justification was that giving issuers flexibility would lead to innovative benefit plan designs and greater consumer choice. Unfortunately, consumers with disabilities and chronic conditions have few choices if issuers put out insurance products that substitute broadly needed healthcare services and items used by the general population while avoiding benefits that are more commonly needed by people with specific disabilities. A plan could increase coverage of EHB categories such as ambulatory patient services, prescription drugs, and rehabilitative services and devices and market itself as offering great coverage for athletes and people engaged in "active living," but the substitution will occur at the expense of EHB categories such as hospitalization, habilitative services and devices, and chronic disease management that are disproportionately needed by people with disabilities and chronic conditions. The actuarial substitution of benefits between EHB categories can be used all too easily to "cherry pick and lemon drop" people with disabilities who are forced by adverse selection into paying more for coverage under fewer and fewer plans that will support their healthcare needs.

For example, the category of "mental health and substance use disorder services including behavioral health treatment" 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 these services in recognition of the important role the benefit plays in helping ensure that adults and children with mental disabilities maximize their health, function, ability to live independently, and ability to participate in society.

Substitution enables states to replace its mental health and substance use benefit category with one that, for example, might exclude (or limit) community-based treatment in favor of residential care where it is not necessary or the most integrated setting for delivery of such services. EHB services in this category must include coverage for all

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medically necessary services, including intensive-home based treatment (e.g., psychotherapy, behavioral management, and medication management services), mobile crisis services and community stabilization, and comprehensive outpatient treatment planning.

Furthermore, the risks for people with disabilities and chronic conditions outlined above are also present if substitution *within* EHB categories is allowed. In the categories that list multiple components, such as mental health and substance use disorder services, and preventive and wellness services and chronic disease management, the components are not interchangeable. For example, an insured person may need community-based mental health services and treatments without needing residential substance use disorder services. This may initially appear to be an argument for allowing tailored benefit offerings within EHB categories so that individuals may buy a product that provides only the benefits they need, but this presumes both that people with disabilities have static treatment needs and that issuers will not engage in profit-driven analyses to offer a myriad of lesser benefits as a substitute for expensive benefits typically needed only by people with disabilities.

The category of rehabilitative and habilitative services and devices speaks to four types of benefits which cannot be substituted for one another, and CMS has recognized the distinct nature of these benefits in its 2016 NBPP final rule⁴ which defines habilitative services and devices as well as rehabilitative services and devices and establishes that limits on the former cannot be less favorable than limits on the latter. In practical terms, the habilitative services and devices needed by a wheelchair user with spinal muscular atrophy in her 30s will not be the same as the rehabilitative needs of a previously non-disabled man who experiences a stroke in his 50s, even though both will draw from the same EHB category. If an issuer were allowed to simply cut out all coverage of wheelchairs by substituting some other service of an equivalent actuarial value, wheelchair users with chronic and/or degenerative conditions will be actively discouraged from seeking that issuer's products.

The EHB categories are properly conceived as a comprehensive set of healthcare services needed by people with and without disabilities once disability is properly understood as a mutable and intrinsic facet of life. No one knows when, how, or for long they or a family member may acquire a disability or enter a period of increased healthcare need. This is the underlying rationale for the existence of health insurance. Substituting benefits should not become a game of chance in the name of theoretical flexibility and innovation. We encourage HHS to eliminate the potential to substitute benefits within EHB categories.

⁴ Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2016, 80 Fed. Reg. 10749 (Feb. 27, 2015).

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

We strongly support the proposed revision to the EHB nondiscrimination policy. People with disabilities and chronic conditions have endured an extensive history of discrimination in insurance benefit design, ranging from annual or lifetime dollar caps on people with specific health conditions to high co-pays/coinsurance on particular types of benefits and quantity restrictions on mental health and long-term therapeutic benefits. For the most part this discrimination has gone unchecked, purportedly justified by an amorphous concept of actuarial evidence and the acceptance that profit could legitimately take priority over medical necessity and recommended clinical practice. DREDF and Bazelon strongly support HHS' proposal in the 2023 NBPP to, first, provide a conceptual framework for judging discriminatory EHB design against accepted clinical practice and, second, provide an expanded set of concrete examples that illustrate presumptively discriminatory benefit design. However, we want to take the opportunity to emphasize that patient-centered goals, patient buy-in, and community integration can and should remain priority considerations in determining the discriminatory nature of benefit design for individuals with disabilities. For example, denial of wheelchair coverage or reimbursing in-patient mental health services over community-based services is, in part, discriminatory benefit design because they take community-based choices and options away from people with disabilities.

Because disability discrimination was so prevalent and accepted in the US private insurance industry, the specific mechanism for the discrimination can be difficult to recognize and remedy when it isn't something obvious like an outright denial of issuance or charging exorbitant premiums to someone disabled. Many of the tools used by insurers to control actuarial risk and costs, such as limiting healthcare delivery to a provider network, requiring prior authorization, imposing cost sharing or quantity limitations, establishing tiered drug formularies, or using other utilization management techniques, are the same tools that can be wielded against consumers with disabilities, sometimes deliberately, and sometimes without regard for their particular impact on people with disabilities. In addition, many of these tools have historically been an avenue to deny necessary behavioral health care. The requirement that benefit designs must pay regard to a contemporary clinical understanding of which healthcare services are necessary for effective care takes away the arbitrary focus on any given insured person's personal characteristics such as race or the presence of disability, and returns to the fundamental rational for providing healthcare: getting people the services, treatments and items they need to attain and maintain well-being and health.

In considering the question of whether peer-reviewed medical journals should be the only or primary source of information to support a charge of benefit design discrimination, we would like to point out that people with disabilities have specific needs that are highly related to healthcare, but do not always fall strictly within the

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purview of medical service or treatments. Long-term services and supports (LTSS) can include such personal care needs as assistance with activities of daily living, chore assistance, supervisory care, and assisted decision-making. These are all facets of living successfully and healthily in the community for many people with significant disabilities yet are not considered "healthcare." Peer reviewed articles relevant to the health and wellbeing of PWD can concern care coordination, patient-centered care, and best practices for meeting LTSS needs but rarely appear in the kind of medical journals listed in the comments to the 2023 proposed rule. An example can be found in a study looking the impact of the resource density of medical and social care on hospitalizations of older adults receiving Home and Community Based Services (HCBS) in Michigan.5 The article has relevance for how insurers structure their provider networks and for clinical best practices in assessing care management and whether a patient has unmet HCBS needs, but it is a peer-reviewed article in a journal devoted to the multidisciplinary field of gerontology rather than a peer reviewed medical journal. As the field of healthcare finally begins to pay attention to the healthcare impact of unequal access to social determinants of health and implicit bias, important and relevant studies may be published in journals that are not strictly medical, but that have deep implications for how medical interventions should be structured and delivered, and this is especially true for people with disabilities and chronic conditions.

Moreover, peer support, for example, is an evidence-based practice that improves outcomes, increases the use of community-based and home-based care, and reduces treatment costs for individuals with mental health conditions. However, new models and best practices for peer-based support emerge regularly, and restriction to evidence-based practices might limit patient access to necessary peer support. We encourage HHS to include peer support credentialing organizations (e.g., International Certification & Reciprocity Consortium, Project LETS National Peer Mental Health Advocates) among its list of organizations that can provide treatment recommendations through professional guidelines.

We also welcome the inclusion of an example of discrimination based on health conditions. We encourage HHS to also add an example that expands on how needed medical care can be more subtly limited by functional limitation and not only an official diagnosis. For example, an issuer's adoption of an exhaustive list of items that will be covered as rehabilitative or habilitative devices is discriminatory if that list completely excludes items commonly needed by individuals with significant mobility limitations such as wheelchairs and scooters, or excludes items such as ventilators commonly needed by individuals with medical conditions that affect their ability to respirate without assistance. Such exclusions are not keyed to specific diagnoses but deeply discourage

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⁵ Kim, Min Hee, and Xiaoling Xiang. "Hospitalization Trajectories in Home- and Community-Based Services Recipients: The Influence of Physician and Social Care Density." *The journals of gerontology. Series B, Psychological sciences and social sciences* vol. 76,8 (2021): 1679-1690. doi:10.1093/geronb/gbaa199.

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people with a range of disabilities and health conditions from enrollment in a plan because medically necessary EHB has been arbitrarily excluded from coverage. We would further suggest including an additional example that illustrates this point as it relates to people with mobility disabilities:

Example: Discrimination Based on Disability or Health Condition

Exclusion of Wheelchair Coverage

- a. Background: According to the World Health Organization, an appropriate wheelchair is the standard of care for people with disabilities who cannot walk or who have difficulty walking. An appropriate wheelchair is one that meets the user's needs and environmental conditions, provides a proper fit and postural support, has properly configured technology, and is safe and durable.⁶
- b. Circumstance: We note that some issuers completely exclude coverage of wheelchairs or place low annual dollar limitations on their coverage (e.g., \$2,000 cap on a \$25,000 power wheelchair). We also note that some states fail to include wheelchairs as a "rehabilitative and habilitative services and devices" in their EHB-benchmark plans.
- c. Rationale: Medically necessary wheelchairs enable people to become mobile, remain healthy, and participate fully in community life. An appropriate wheelchair can increase an individual's physical function, level of activity, and control over their own bodies and movements. With proper fitting and customization, it can improve respiration and digestion, prevent lifethreatening pressure sores, minimize joint sprain and pain, and reduce the progression of an individual's impairment or secondary conditions. It also increases access to health care, education, employment, and family life. These factors, in turn, significantly improve an individual's independence and quality of life.⁷

⁶ WORLD HEALTH ORG., *Guidelines on the Provision of Manual Wheelchairs in Less Resourced Settings* 21 (2008), *available at* https://www.who.int/disabilities/publications/technology/English%20Wheelchair%20Guid

elines%20(EN%20for%20the%20web).pdf.

⁷ See, e.g., World Health Org., *supra* note 12 at 23; Alicia M. Koontz, et al., *Wheeled Mobility*, 2015 BIOMED. RESEARCH INT'L (Apr. 1, 2015) (introducing Special Issue focused on wheelchairs), *available at* https://www.hindawi.com/journals/bmri/si/701370/; Silvia Yee, Mary Lou Breslin, et al., *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity*, NAT'L ACADS. SCI., ENG'G, & MED. (2017), *available at* https://dredf.org/wp-content/uploads/2018/01/Compounded-Disparities-Intersection-of-Disabilities-Race-and-Ethnicity.pdf.

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d. Conclusion: Excluding coverage of wheelchairs in a plan benefit design is presumed to be discrimination on the basis of disability and health condition under § 156.125. Excluding coverage that is medically necessary in a subset of individuals presumptively conflicts with the prohibition under §156.125 against discriminatory benefit design.

Additionally, another form of disability-based discrimination under Section 504 is the needless segregation of individuals with disabilities. *Olmstead v. L.C.*, 527 U.S. 581 (1999). HHS should prohibit marketplace plans from taking benefit design actions that result in the needless segregation of people with disabilities to receive coverage for services and supports.

HHS should prohibit insurers from covering a service (such as personal care or an item of durable medical equipment) for individuals in institutional settings but not covering the same service for individuals living in their own homes or other community settings. Similarly, services should not be covered in greater amounts for individuals in segregated settings.

HHS should prohibit states from making EHB coverage decisions that result in people with disabilities 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 non-discrimination provision if it results in individuals being served in segregated settings such as hospitals, nursing homes, ICF/DDs or board and care homes and covering the services to support them in integrated settings would not be unduly expensive.

IX. Standardized Plan Options (§ 156.201)

DREDF and Bazelon support HHS' 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 readily compare plans standardized cost-sharing requirements across plans, allowing consumers with particular health needs to investigate factors such as premiums that directly impact on the affordability of the plan, and balance those considerations against their own specific quality and coverage needs such as provider network, quality of services, and drug formularies. 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 support requiring standardized plans to use fixed copays instead of coinsurance, which disproportionately burdens persons with chronic illness and disabilities. DREDF has investigated and verified a wide trend across QHPs in California that imposed "100% coinsurance" for certain rehabilitative and habilitative devices, rendering coverage of those EHB items illusory. Item-specific coinsurance fees

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can also be very difficult for prospective enrollees to uncover and require chasing down information through layers of plan representatives and brokers.

By improving affordability to services and items 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 happy to see the federal government extending this consumer-friendly policy to federally facilitated exchanges and state-based exchanges that use the federal platform.

X. Network Adequacy (§ 156.230)

We welcome HHS revisiting network adequacy regulations to ensure that QHP enrollees have meaningful access to all essential health benefits. We also support HHS' 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 establishing the same standards for SBEs that it uses in the FFE; states can perform their own reviews of network adequacy, but their standards and review process should be at least as stringent as established federal standards and process. We emphasize that network adequacy reviews, whether performed by HHS or by states, must include direct testing of both primary and specialty care, such as secret shopper surveys, or data systems that capture appointment details and include scenarios in which secret shoppers have characteristics such as high weight or mobility disabilities that we know impact on the willingness of providers to accept patient referrals.8

We strongly support HHS' 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. However, we recommend greater inclusion of special service providers in service areas that we already know present long wait times for people with disabilities. For example, DREDF has heard repeated reports of wheelchair users with complex rehabilitation needs that must wait weeks or even months months to get a

⁸ Lagu T, et al., *Access to subspecialty care for patients with mobility impairment: A survey.* Ann Intern Med. 2013;158(6):441-446.

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needed wheelchair or wheelchair repair, leaving them without mobility within their communities or homes.

We also support HHS' 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 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, and helping to make diagnostic testing and screening services available when primary care provider offices are not open.

We strongly support HHS' proposal that for plans that use tiered networks, to count toward the issuer's satisfaction of the network adequacy standards, providers must be contracted within the network tier that results in the lowest cost-sharing obligation. In addition, we urge HHS to provide clarity in this rule about QHPs obligations to their enrollees when they are unable to meet time and distance standards or appointment wait time standards. Even the most robust networks will occasionally be unable to provide extremely rare and specialized services, and may experience times when providers are temporarily unavailable, resulting in enrollees having to travel further and wait longer to access care. This point has been driven home over the last few months as many health care providers have 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. Of relevance here is the disparate degree to which people with vision, hearing, mobility, or cognition disabilities experienced delayed or foregone medical care as well as food insecurity during the pandemic.⁹

We support HHS' 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. For people with disabilities, the broadened availability of telehealth has been a mixed blessing. For some people with disabilities, it has enhanced access to healthcare information, consultation and services while enabling them to continue to isolate. This has been particularly important for people with disabilities and chronic conditions that leave them particularly vulnerable to infection and the risk of hospitalization or death from COVID-19.

On the other hand, we have also heard reports of how people who are Deaf, Hard-of-Hearing, and who have other communication disabilities have been shut out of telehealth, particularly when dealing with larger managed care providers who use

⁹ Lama Assi, Jennifer A. Deal, Laura Samuel, Nicholas S. Reed, Joshua R. Ehrlich, Bonnielin Swenor. Access to food and health care during the COVID-19 pandemic by disability status in the United States, Disability and Health Journal, 2022,101271, https://doi.org/10.1016/j.dhjo.2022.101271.

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proprietary video/telephone systems for patient-provider appointments. In short, these in-house systems have not prioritized disability access or compatibility with such accommodation measures as sign language interpretation or captioning. As a result, patients with communications disabilities are left struggling to figure out non-integrated communication systems where the provider is on one computer screen while captions appear on a separate secondary device; the patient is unable to lip-read or look at the provider's face, is not necessarily given additional time for the appointment, and must constantly overcome real-time gaps in what can be understood in the appointment. Some providers simply place responsibility for accessible communications entirely on the patient, or only offer stopgap measures in real time without ever addressing the systemic access problem. Over the last few years we have been learning a lot about the use of telehealth, and gathering this information will help inform future rulemaking about the role of telehealth providers in comprising a network sufficient to deliver covered services to all enrollees. 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 while encouraging special attention on the need for fully integrated communication accessibility for people with disabilities and non-English language users.

We support HHS' proposal to raise the ECP participation standard to 35 percent. We urge HHS to require QHPs to meet this standard for each category of ECP rather than for all ECPs take as a whole, to ensure that QHP enrollees have adequate access to all of the important types of ECPs which range from Ryan White providers to FQHCs. We strongly support HHS' proposal that for plans that use tiered networks, to count toward the issuer's satisfaction of the ECP standards, ECPs must be contracted within the network tier that results in the lowest cost-sharing obligation.

XI. 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. The size of insurer rebates in 2020 and 2021, exceeding \$2 billion, shows the degree to which premium revenues have either exceeded expectations or clinical services have not been provided below expectations. There is an additional factor though as CMS has identified egregious examples of insurers using various tactics to avoid paying rebates owed to consumers. For example, some bonuses to providers are triggered only when the MLR rebate provision is triggered – meaning they relate to the insurers' finances, not provider performance – inflating claims by as much as 30 to 40 percent. Also, insurers have attributed indirect expenses to quality improvement expenses – including the purchase of artwork and travel and entertainment expenses – to inflate health spending and deprive consumers of rebates. We support limiting the definition of a quality improvement activity to include only direct expenses that are clearly related to improved quality or clinical standards. However, we also recommend that the MLR provisions explicitly recognize that undertaking quality or clinical improvements for people with disabilities, such as subsidizing the acquisition of accessible medical and

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exam equipment for network providers, may count as a quality improvement activity that will improve health outcomes for a population group that is subject to health inequity within the meaning of Section 2717 of the Public Health Service Act and Section 1311 of the ACA.

XII. Solicitation of Comments Regarding Health Equity, Climate Health, and Qualified Health Plans

DREDF and Bazelon enthusiastically support requirements for QHPs to collect voluntary information on each enrollee's race, ethnicity, gender, sexual orientation, primary language and disabilities. Asking enrollees to provide information on these characteristics as demographic information is essential to uncovering the full range of persistent health inequities associated with any one of these characteristics, as well as identifying the as yet unknown impact of compounded disparities occurring among individuals who have a number of these characteristics.

The pandemic highlighted the multiple data collection gaps that exist for people with disabilities, from the lack of disability and functional impairment demographic information on death certifications to a dearth of detailed knowledge about the functional impairment and accommodation needs of HCBS users in the community. HHS can play a critical leadership role among all federally conducted and funded health programs in calling for the broad adoption of validated functional impairment questions such as the 6 question disability set used in the American Community Survey, as well as initiating ongoing research on any gaps that exist within that set and how those gaps could be addressed. For example, does the set fully capture persons who have mental health disabilities or speech disabilities without attendant cognitive or hearing impairments, and how can severity of impairment best be captured within an adapted set of questions?

Recommendations already exist from the <u>Institute of Medicine</u>, <u>the Williams Institute at UCLA</u>, ¹⁰ and others will be forthcoming that draw on both studies and stakeholder input for demographic data collection on other characteristics. Demographic data collection on disability deserves the same attention and rigorous study so that QHPs can efficiently capture data relating to disability. We agree with many of our fellow healthcare advocates that the ultimate purpose of collecting demographic information from enrollees is to advance health equity and health quality. As such, HHS should also set standards for QHPs to engage in systematic review of enrollee data, to review the use of artificial intelligence and algorithms for analyzing data for implicit bias, and to engage in actions to address the disparities that are revealed through data collection.

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/

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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. We still strongly recommend that QHPs be required to also collect this data as some individuals will be more comfortable providing demographic data to their plan or provider who will then work in conjunction with the QHP, as opposed to a government agency in charge of enrollment in a public service program. But HHS' own commitment to collecting and utilizing demographic data to address health disparities and improve health equity is important to establish the leadership, and correct the longstanding signal that demographic data collection on disability is unnecessary or fulfilled by having a medical diagnosis in the electronic health record.

Finally, DREDF and Bazelon support a requirement for QHPs to obtain NCQA's Health Equity Accreditation. HEA's standard for accreditation introduces QHPs to the importance of data collection, how data collection is critical for uncovering the existence and depth of health disparities, and ways in which plans can use health disparity data to improve health equity. As NCQA has now moved to initiate a "Health Equity" Accreditation Plus" standard, broader use of the Health Equity Accreditation will help prepare plans for the next steps in achieving greater health equity among members and enrollees. However, the HEA lacks specific standards that address people with disabilities. We recommend that HHS work with NCQA and stakeholders to meet the urgent need to include members with disabilities, including members who have already been identified as subject to health inequity because of other personal characteristics. If disability is not measured, people with disabilities are not counted and the health and healthcare disparities they experience remain buried. The solution must begin with comprehensive and granular data collection of functional impairment status across the entire patient population. HHS should retain ultimate responsibility for oversight of QHP accreditation, and the accreditation materials provided by QHPs pursuing accreditation should be publicly available (and of course stripped of any personally identifying information and aggregated).

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XIII. Conclusion

Thank you again for the opportunity to comment on the many important issues raised in the 2023 NBPP proposed rule for people with disabilities. If you have any questions on the above, please contact Silvia Yee (syee@dredf.org, 510-644-2555 x5234) or Carly Myers (cmyers@dredf.org, 510-644-2555 x5250) at DREDF, or Brit Vanneman at Bazelon (britv@bazelon.org, 202-467-5730 x1306). For future iterations of the NBPP notice, we very much hope that we will have a fuller period of time than just over three weeks to provide the perspectives, data, and relevant experiences of people with disabilities under the ACA.

Sincerely,

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