



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

December 22, 2014

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

Re: Comments on *PPACA: Notice of Benefit and Payment Parameters for 2016*. File code:  
HHS-9944-P

Thank you for the opportunity to comment on the proposed rule *Notice of Benefit and Payment Parameters for 2016*. The continued implementation and operation of Affordable Care Act (ACA) programs, including the Health Insurance Marketplaces, is crucially important to the millions of Americans with disabilities and chronic conditions. The Consortium for Citizens with Disabilities (CCD) is a coalition of more than 100 national consumer, advocacy, provider, and professional organizations advocating on behalf of people of all ages with physical and mental disabilities and their families. The CCD Health Task Force is working to ensure that the implementation of the ACA achieves access to high quality, comprehensive, affordable health care for all Americans, including people with disabilities and chronic conditions. On behalf of the CCD Health Task Force, we thank you for your leadership on the ACA and respectfully submit the following comments.

**Consumer Tools and Navigator Standards - §155.205**

CCD continues to strongly support strong accessibility standards for people with disabilities and limited English proficiency. We wish to reiterate our comments from October 31, 2011 that “disability be viewed as a litmus test for all consumers of exchange products and services.”<sup>1</sup> If consumers with special needs cannot navigate the exchange, either on their own via the website, or through navigators or non-navigator assistance personnel, then the exchange is unlikely to realize its key objectives of providing access to quality insurance options and facilitating consumer choice of health insurance products.

CCD supports HHS’s proposal to require exchanges, issuers, agents and brokers to provide oral interpretation services including telephonic interpretation in at least 150 languages. We appreciate that HHS did not propose this standard for navigators and non-navigator assistance personnel because of the potential burden on small community nonprofit organizations that are encouraged to become navigators or otherwise assist with outreach and enrollment. However,

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<sup>1</sup> CCD Comments on Establishment of Exchanges and Qualified Health Plans, October 2011: [http://www.c-c-d.org/fichiers/Exchange\\_regs\\_final.pdf](http://www.c-c-d.org/fichiers/Exchange_regs_final.pdf)

accurate and appropriate translation services are crucial for people with limited English proficiency, especially if they have disabilities or chronic conditions. Certain disabilities often disproportionately affect certain minority groups, and CCD encourages a strong standard of language access.

We propose two options for Navigators and non-Navigator assistance personnel:

1. HHS contract with a telephonic interpretation service directly and make that service available to all Navigator and non-Navigator assistance personnel grantees.
2. Navigators and non-Navigator assistance personnel be expected to provide access to the telephonic interpretation services in 150 languages through referral to the exchange.

Language access must also include those who use American Sign Language (ASL), so we strongly encourage HHS to use similar methods to help community-based and nonprofit organizations provide language access for ASL users. We wish to again reiterate our recommendation from October 31, 2011 that at least one type of navigator entity be required to demonstrate a proven track record of serving individuals with disabilities and their families.<sup>2</sup> Organizations accustomed to serving people with disabilities are more likely to provide meaningful access for all people, regardless of disability, language, or other need.

HHS specifically “solicits comments on whether they should require more specific accessibility standards under other requirements under §155.205(c), such as...auxiliary aids and services to individuals with disabilities”. CCD thanks HHS for asking about specific accessibility standards for individuals with disabilities. Rather than attempt to list all of the accommodations and accessibility standards that individuals might need, CCD encourages HHS to hold exchanges, navigators, non-navigator assistance personnel, and any other entity involved in ACA programs, particularly those receiving federal funds, to their accessibility obligations under the Affordable Care Act and Section 504 of the Rehabilitation Act. CMS should also work with HHS Office of Civil Rights to monitor and enforce these existing accessibility obligations among Navigator and non-Navigator entities as a necessary part of the agencies’ non-discrimination activities under Section 1557.

## **Essential Health Benefits Package**

### State Selection of Benchmark - §156.100

CCD appreciates the recognition that benchmark plans used to determine the essential health benefits for each state need to be updated. Basing them on 2014 plans is an improvement. However, we would still prefer to see a different process used to determine essential health benefits that better meets individual consumers’ needs and is more consistent across the country. We urge HHS to use the lessons learned in 2014 and 2015 to develop a unified national EHB standard. The ACA directs the Secretary of HHS to define the EHBs, and CCD continues to prefer a federally-defined set of EHBs. Clear federal minimum EHB standards are necessary to ensure that vulnerable populations can access comprehensive care that consistently meets their needs.

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<sup>2</sup> CCD Comments on Establishment of Exchanges and Qualified Health Plans, October 2011: [http://www.c-c-d.org/fichiers/Exchange\\_regs\\_final.pdf](http://www.c-c-d.org/fichiers/Exchange_regs_final.pdf)

Since an alternative approach is not being proposed at this time, and HHS is continuing to use the benchmark process to define essential health benefits for each state, we support using 2014 plans as the benchmark, but urge HHS to implement this for the 2016 and not the 2017 plan year.

#### Provision of Essential Health Benefits - §156.115

##### *Habilitation and Rehabilitation*

**CCD fully supports the comments submitted by the Habilitation Benefits Coalition.** We would like to reiterate, in addition to strong support for a uniform definition of habilitation, the need for consumers to have meaningful access to information about habilitation and rehabilitation coverage. For families to make informed choices about their health insurance options on the exchanges, information about rehabilitative and habilitative benefits must be accessible and understandable, including information on therapies covered, visit limits, and how cost-sharing applies. For a family or individual with a disability, coverage of these services and devices is one of the most important health care coverage decisions they will make, but over 90% of plans reviewed by the American Occupational Therapy Association did not include this information.<sup>3</sup> HHS should require that this information be included in Summaries of Benefits and Coverage (SBCs). The fact that some QHPs' SBCs – albeit too few at less than 10% - included this information is an indication that all carriers could include it without modifying the SBC format or creating an undue burden.

##### *Mental Health Coverage*

In addition to our strong support for the revision of the habilitation benefit and the comments of the HAB Coalition, we take this opportunity to point out that the same concerns that lead HHS to revise the definition of habilitation benefit apply to the mental health benefit as well. The Department should also revise the definition of the mental health benefit to identify a minimum scope of coverage. In selecting benchmark plans, almost every state chose or defaulted to a small group plan, plans that historically have offered very limited mental health benefits. These plans were also not previously covered by the Mental Health Parity and Addiction Equity Act (MHPAEA) and most included inadequate coverage of mental health services to meet the requirements of parity. In order to comply with the parity and non-discrimination requirements of the ACA, benchmark plans were then supplemented with some mental health services. However, the medical necessity criteria, benefit exclusions, treatment limitations, use of utilization management, and cost-sharing and other financial requirements remain variable, leading to uncertainty about what is covered and inadequate coverage of mental health services.

In addition to the issue of inadequate coverage, the mental health EHB must include sufficient services to meet federal requirements, including: (1) that mental health services be provided at parity with medical services in each category, and (2) that coverage decisions, reimbursement rates, and benefit design not discriminate based on disability (and hence do not foster needless institutionalization).

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<sup>3</sup> American Occupational Therapy Association, Analysis of Rehabilitation and Habilitation Benefits in Qualified Health Plans, 2014: <http://www.aota.org/-/media/Corporate/Files/Advocacy/Health-Care-Reform/Essential-Benefits/EHB-research-project.pdf> (Page 8).

Parity requires that limits on the scope and duration of treatment must be applied no more restrictively to mental health benefits than to medical/surgical benefits.<sup>4</sup> Parity also requires that plans must offer mental health services in the same scope as medical services; for each medical service covered, analogous or comparable mental health services must be covered.

The ACA's non-discrimination provisions prohibit health plan issuers from designing plans in a way that discriminates against individuals with disabilities, including mental disabilities and prohibit discrimination in making decisions about coverage, reimbursement rates, establishing incentive programs, and designing benefits. One very important form of disability discrimination for people with psychiatric disabilities is the needless segregation of individuals with disabilities.<sup>5</sup> To give effect to this part of the ACA's non-discrimination provisions, the MH/SUD benefit must cover services that prevent people from being served needlessly in segregated settings. For example, failure to cover services essential for people with psychiatric 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 a hospital or nursing home.

These requirements of the ACA demand more coverage than is typically provided now and we urge the Department to adopt a uniform definition of MH/SUD services to minimize the variability in benefits and lack of coverage. The Department should identify a minimum scope of mental health services that plans must cover to comply with the ACA's parity and nondiscrimination requirements and the requirement that EHB take into account the "needs of diverse segments of the population, including . . . persons with disabilities." This should include an array of services that are essential to enabling individuals with serious mental illnesses to be integrated into their communities, including community-based services such as crisis outreach and intervention, peer support programs, and programs designed to serve individuals where they live and work in the community.<sup>6</sup>

#### Collection of Data to Define Essential Health Benefits - §156.115

CCD supports HHS's proposal to re-codify this requirement to the regulations. Up-to-date and detailed information regarding the definition of each state's Essential Health Benefits (EHB) package is critical to ensuring HHS has the ability to enforce the regulations related to provision of EHB. As such, we urge HHS to require states to submit this data annually, including any state

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<sup>4</sup> 42 U.S.C. § 1185a(a)(3)(B)(iii)

<sup>5</sup> *Olmstead v. L.C.*, 527 U.S. 581 (1999). See also 28 C.F.R. § 35.130(b)(7) (covered entities shall administer services to individuals with disabilities in the most integrated setting appropriate to their needs). See also, Centers for Medicare and Medicaid Services, *Guidance to States using 1115 Demonstrations or 1915(b) Waivers for Managed Long Term Services and Supports Programs* (May 20, 2013) ("States that exclude specific services from their [service packages] will be expected to routinely assess whether there is any negative impact as a result of the exclusion and whether there are any violations of federal requirements, including the ADA or Olmstead. [...] States must be prepared to take appropriate action as necessary to ensure no violation of federal requirements to provide services in the most integrated setting, including violations of ADA and Olmstead requirements, and to promptly remediate any violations found.").

<sup>6</sup> Examples of such evidence-based practices include programs such as Assertive Community Treatment, Mobile Crisis Outreach Teams, the use of peer support specialists on mental health treatment teams, and programs such as supported employment or supported housing. Emerging best-practices are ever evolving, so insurance companies should remain flexible to adapt and cover new effective practices as they emerge through research.

modifications of the selected or default benchmark plan, and that HHS require the data to include sufficient detail to fully determine how EHB is defined; listing broad categories of covered benefits is not sufficient. We refer to our original comments on the collection of data to define Essential Health Benefits submitted July 5, 2012<sup>7</sup> where we encouraged HHS to insert the National Association of Insurance Commissioner's definition of habilitation services in the data collection chart and add sub-rows specifying benefits that commonly all under this benefit category. The adoption of NAIC's definition for habilitation in §156.115 of the proposed rule further supports this proposal. Finally, we encourage HHS to be transparent with regards to data obtained and to post such data in an easily accessible location on the Department's website.

#### Prescription Drug Benefits - §156.122

CCD applauds the Department's efforts to identify improved processes and standards for prescription drug benefits to meet EHB requirements. Our constituents are understandably frustrated when the medicines they rely on to manage their conditions are not accessible due to formulary exclusions, inaccurate information, un-affordable cost-sharing, or other reasons. In general, we believe the reformed approaches described will go a long way toward the goal of affordable coverage and access to the most promising and timely drug treatments for every enrollee.

We support the need to replace the previous 'one drug per category or class' drug count standard of the US Pharmacopeia (USP) with a system better suited to the comprehensive drug benefit needs of QHP enrollees. As described in the proposed rule's preamble, the US Pharmacopeia (USP) classification system was designed for the Medicare Part D program, which is a different population than the qualified health plans (QHPs). Using this standard for QHPs has resulted in numerous drugs not being covered that are needed by patients, including newly approved medications, and plans removing necessary drugs mid-year. We urge HHS to move forward with retaining, at a minimum, the current greater than one drug or the number of drugs covered by the benchmark requirement using either the most recent AHFS or USP system, and using the most granular level of either counting system *in tandem with the expert recommendations of the P&T committee*.

Using the American Hospital Formulary System (AHFS) and/or updated USP (version 6) as a framework for the decisions of pharmacy and therapeutics (P&T) committees could result in more robust, equitable, and clinically appropriate formularies provided that greater oversight standards than proposed for P&Ts are established and upheld. We support HHS's expectation that the P&T committee members include experts in chronic diseases and in the care of individuals with disabilities. A minimum number of P&T members with demonstrable clinical expertise in the conditions with which enrollees live is also essential. Further, we recommend that plans be compelled to seek outside expertise from experts in rare disorders, including pediatric disorders, and enrollees with conditions whose treatments are under review and/or their family members.

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<sup>7</sup> CCD Comments regarding Data Collection to Support Standards Related to Essential Health Benefits: Recognition of Entities for the Accreditation of Qualified Health Plans: [http://www.c-c-d.org/fichiers/EHB\\_Comments\\_on\\_Data\\_Collection\\_final.pdf](http://www.c-c-d.org/fichiers/EHB_Comments_on_Data_Collection_final.pdf)

P&T committee accountability should include public disclosure of members, conflict of interest standards and disclosures, and documented procedures for reviewing new drugs and new uses of drugs. We are concerned about the practice of P&T committees developing their own conflict of interest standards, especially in light of a 2013 OIG report on P&T committees and Part D plans.<sup>8</sup> We urge HHS to identify and adopt a more publicly accountable conflict of interest standard for P&T committees serving qualified health plans.

Because payers' strict reliance on published evidence as a basis for coverage determinations has been problematic for many of our constituents, we are pleased to see the breadth of source documents that must be included in P&T committee reviews.

Finally, with regard to the initiation of these requirements, since commercial health plans are already familiar with P&T committees and the AHFS classification system, we encourage the Department not to wait until 2017 to initiate these requirements. If HHS uses the USP system in 2016, plans should be required to use USP Version 6.0 and not 5.0. Version 6.0 was finalized in February 2014 and is more current and reflective of today's FDA approved medications. For the AHFS to be used, it will have to be made accessible to the public.

We agree that enrollees and others would benefit from greater clarity and uniformity in processes involving requests for exceptions to a formulary. We support the proposed requirement that covered exceptions count toward enrollees' annual out-of-pocket maximum, timeframes for expedited exception requests, and IRO review of exception requests resulting in a coverage denial. We too find that it takes time for many new enrollees to adapt to formulary restrictions, prior authorization, and step therapy requirements. Temporary coverage for non-formulary drugs is important for the continuity of care and should be assured for more than the first 30 days of coverage. When an exception to the formulary is granted, enrollees should be assured continued coverage for the duration of the prescription and refills.

We strongly support stricter requirements for the provision of accurate, up-to-date and machine-readable formulary lists where they can be seen by the public. We urge stronger enforcement of the current requirement that links to formularies appear on the Summary of Benefits & Coverage. We agree that full disclosure of cost-sharing requirements is critical, since information about drug tier placement is relatively meaningless to enrollees without it. Finally, we greatly appreciate greater flexibility with regard to enrollees' preferences for getting their prescriptions directly from pharmacies in their communities.

We are also very supportive of the proposals to increase formulary and provider transparency. In order for patients to select the plans that best meet their individual health care needs, they must have access to easy-to-understand, detailed information about plan benefits, formularies, provider networks, and the costs of medications and services. While we have seen some transparency improvements with the 2015 plans, many plans still do not have a direct link to a plan's formulary on the "Summary of Benefits and Coverage" as required by the ACA. In order to find the formulary multiple searches must be conducted for some plans. The proposed rule reiterates the ACA requirement, and proposes that each plan publish up-to-date, complete

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<sup>8</sup> Department of Health and Human Services Office of the Inspector General, Gaps in Oversight of Conflict of Interests in Medicare Prescription Drug Decisions': <http://oig.hhs.gov/oei/reports/oei-05-10-00450.pdf>.

formularies with tiering and any restrictions on accessing the drug. HHS is also seeking comment on whether formulary tiering information should include cost sharing information, including pharmacy deductible and cost-sharing. We are highly supportive of all these common sense proposals that help people make the best decisions to meet their needs. Additionally, since plans are employing the use of co-insurance more frequently, plans should detail what the actual cost sharing will be in dollar terms. By not detailing this information, people are left in the dark when it comes to how much they will have to pay for a drug or service.

We also are very supportive of the proposal to require plans to submit drug formularies and provider lists in machine-readable file. Currently, there is no standard formulary design and some have search capabilities while others do not. We would very much like to see an interactive web tool such as a plan finder or benefit calculator that matches an individual's prescriptions and provider needs with appropriate plans (such as the one utilized by the Medicare Part D program). Submitting information in a standard machine-readable format can assist in developing such tools. We also support the inclusion of other data in a machine-readable format to facilitate research (see further comments on data collection above).

We are highly supportive of providing people with the choice of how they receive their prescriptions and prohibit the practice of a mail-order only option. As the proposed rule describes, there are legitimate instances in which an individual may want to access a retail pharmacy and can benefit from interaction with a pharmacist. We see no reason why this option should be delayed until 2017 and believe it should be implemented in 2016.

#### Prohibition on Discrimination - §156.125

**CCD fully supports the comments of the Habilitation Benefits Coalition regarding discrimination.** CCD has been concerned about discrimination by issuers on the basis of age, diagnosis, or condition for some time, particularly in the area of habilitation. CCD sees two potential areas of discriminatory benefit design: 1) new benefit designs by QHPs designed to discourage enrollment of certain individuals into plans, 2) historically discriminatory benefit designs apparent in benchmark plans and continued into QHP coverage.

We strongly support HHS's reminder to issuers about discriminatory practices such as labeling certain benefits as pediatric only or discouraging enrollment of individuals with certain chronic conditions through drug formulary limitations. We appreciate HHS's clear guidance to issuers and States that they should not discourage enrollment of certain individuals with chronic health needs or certain functional limitations with discriminatory benefit designs. Additionally, we support HHS's assertion that it will notify a QHP issuer when it sees an indication of a reduction in the generosity of a health benefit when this reduction is not based on "clinically indicated, reasonable medical management practices."<sup>9</sup> We also urge HHS to conduct an examination of traditional medical management techniques, such as prior authorization, that may be used as nuanced mechanisms of discrimination to exclude or discourage individuals with disabilities from services unnecessarily.

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<sup>9</sup> See *Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2016*, proposed rule, Vol. 79, No. 228 of the Federal Register at p. 70717 published on Wednesday, November 26, 2014 at p. 70723.

With regards to benchmark plans, we strongly encourage HHS to consider ways in which the agency can actively monitor and review existing health benefit levels for discriminatory practices. Using benchmark plans to define EHB has imported discriminatory insurance practices into the exchanges. The governing bodies of some state exchanges, such as California's Covered California Board, have noted in federal comments and to the public that existing coverage limitations and benefit design features of the benchmark were continued into the EHB definitions for that state, including historically discriminating benefit designs. For example, certain power wheelchairs and other complex rehabilitation technology particularly useful to people with certain conditions have been historically excluded from coverage. It logically follows that states have not engaged in thorough review of the chosen benchmark with benefit design discrimination in mind. Mental health and substance use disorder services, prescription drugs, and rehabilitative and habilitative services and devices are of particular importance to people with various disabilities and the insurance policies upon which benchmarks are based are rife with historical practices in which benefit and coverage limitation decisions are based purely on financial concerns, and little or no actuarial or clinical evidence.

We recommend that HHS develop a concrete and comprehensive plan, in conjunction with the HHS Office for Civil Rights (OCR), to gather input from disability advocates and consumers on existing examples of discriminatory benefit design in policies and in practice. HHS and HHS OCR should work together to develop procedures for how policy reviews will be triggered, as well as how to administer random reviews for QHP compliance with non-discrimination requirements. A pattern of HHS OCR complaints concerning a particular aspect of discriminatory benefit design is a necessary but not sufficient means of triggering policy review. Relying solely on complaints places too great a burden on consumers to understand when and how a policy's terms of coverage for a needed benefit are discriminatory. HHS and HHS OCR should work out additional ways to monitor for discriminatory benefit design, as well as enforcement mechanisms to bring plans into compliance with non-discrimination laws and regulations. HHS and HHS OCR's work together on a plan for ensuring non-discrimination in benefit design should have distinct goals, clear timelines, and measures to ensure ongoing public accountability and transparency. CCD does not believe that historical benefit design practices can be thoroughly rooted out of the exchanges without such a deliberate approach.

We also look forward to further implementation of the anti-discrimination provisions of the ACA through the actions of the HHS Office for Civil Rights and promulgation of regulations on section 1557 of the ACA.

### **Cost-Sharing Requirements - §156.130**

**We support the comments of the National Health Law Program with regards to cost-sharing.** People with disabilities are disproportionately low-income, disproportionately use a high level of specialty medical services, and disproportionately rely on out-of-network providers. Cost-sharing is a central concern for people with disabilities in QHPs.

### **Network Adequacy Standards - §156.230**

CCD fully supports the comments of the Habilitation Benefits Coalition with regards to network adequacy.



We commend HHS for highlighting the importance of seamless care transitions. We recommend requiring issuers to offer out-of-network access and continuity of care (COC) to new enrollees, as well as current enrollees in particular circumstances. People with disabilities often have long-standing and vital relations with providers, and specialists in particular, who have non-replicable knowledge about how an individual's disabilities, chronic conditions, and treatments/drugs interact. In these circumstances where enrollees are engaged in an ongoing course of treatment, the enrollee should be able to maintain ongoing out-of-network relations with the provider until it is possible to change providers. At a minimum, we support the proposed 30-day standard.

We also recommend extending continuity of care protections to enrollees who have chosen a plan in reliance on incorrect information in a provider directory or from service representative, or whose provider ends relations with the plan during the year. Each change leaves the individual without needed medical expertise unexpectedly at no fault of their own. Plans should also be required to automatically extend these COC protections to enrollees with disabilities upon first visiting an out-of-network provider who the individual reasonably expected to be in the plan's network, rather than have the requirement only be triggered by a formal request from the enrollee.

We support the clarification that the network adequacy provisions apply only to QHPs that use a provider network, as well as with the exclusion of out-of-network providers from network adequacy. We assume that this means that the network adequacy provisions apply whenever a QHP has a product that limits enrollees to a provider network, even if the QHP has other product lines that have unrestricted access to providers or has variable provider networks available to different product enrollees. We recommend that §156.230 specify that the network provisions will be applied to each provider network for QHPs that operates multiple provider networks, and will not simply be applied to the QHP's overall network of provider contracts.

We support the changes intended to require greater transparency and timeliness of information in provider directories. We recommend the addition of language that requires the QHP to ensure that the online publication of the directory is made accessible in alternative formats and non-English languages in accord with federal and/or state requirements.

#### Physical Accessibility

CCD strongly supports the provision of physical accessibility as part of network adequacy standards. Physical accessibility should be 1) considered to determine the adequacy of the network for all enrollees and 2) made available to enrollees in provider directories to help them choose plans and providers. We also support training for providers on disability competence and reasonable accommodation.

Providers with inaccessible facilities and equipment are essentially not part of the provider network for enrollees with disabilities. If an enrollee cannot enter the facility, use the equipment, or communicate with the clinician, that provider is completely unusable to the enrollee and may as well not be in the network. When choosing plans, consumers must know if they and their family members will be able to use the services of that provider. This information must be included in provider networks so consumers can make meaningful choices.

We strongly recommend the addition of physical access information (e.g., all structural accessibility elements as well as diagnostic and examination equipment), *as well* as information concerning the provider/offices' participation within the last 2 years in a training on disability competence and reasonable accommodations/policy modifications.

We reiterate our comments submitted February 25, 2014 with regards to the Letter to Issuers on Federally-Facilitated and State Partnership Exchanges to encourage issuers to include detailed accessibility information (e.g., “exam table lowers to \_\_\_ inches,” “platform scale available for wheelchair users,” “bathroom meets ADA Accessibility Guidelines,” “transfer assistance provided upon request,” “alternative formats such as Braille, large font or electronic disc or mail available upon request,” “Sign language interpretation available upon request,” “examination room with \_\_\_ turning radius available upon request,” and/or “extended appointment time available upon request when facilitated communication is required in the appointment.”)<sup>10</sup> At the very least, provider directories should provide contact information for customer representatives who will assist health plan members and the public to determine whether and which network providers have the accessibility features that a member or perspective requires to receive effective health care services. The physical access assessment should be done by trained QHP employees or 3<sup>rd</sup> parties and not simply self-reported by providers.

CCD also encourages HHS to consider the guidelines of the US Access Board on Medical Diagnostic Equipment for guidance on physical access concerns important to people with disabilities.<sup>11</sup>

#### Transparency and Access to Data

We support HHS's proposal to require issuers to make available information about provider networks and drug formularies in a machine-readable files. The ACA and establishment of exchanges created a new opportunity to gather data and conduct research on health and health insurance. We support the proposal to include provider network and drug formulary information in machine-readable files and encourage HHS to release additional data, including benefit information and quality data, in machine readable formats to facilitate transparency and research on health care. All data should be released in formats accessible through screen-readers and other technologies used by people with disabilities.

#### Essential Community Providers - §156.235

CCD supports HHS's effort to ensure that more providers are included as essential community providers (ECP) in qualified health plans by requiring at least one ECP from each ECP category. We have some additional suggestions that could further improve the access to these essential providers for people with disabilities.

We support the expansion of the ECP definition to providers who serve primarily low-income populations and medically under-served communities. While not commonly part of the network

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<sup>10</sup> Consortium for Citizens with Disabilities Comments Regarding Letter to Issuers on Federally Facilitated and State Partnership Exchanges, February 2014: [http://www.c-c-d.org/fichiers/letter\\_to\\_issuers\\_for\\_taskforce.pdf](http://www.c-c-d.org/fichiers/letter_to_issuers_for_taskforce.pdf)

<sup>11</sup> See United States Access Board, Recommendations on Standards for the Design of Medical Diagnostic Equipment for Adults with Disabilities. <http://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/advisory-committee-final-report>

of commercial health insurance issuers, these providers, as the Department noted, are important access points in low-income and medically under-served communities. These providers also have invaluable experience serving people with disabilities. In fact, some providers, including Children's Hospitals, Ryan White Providers, and Community Behavioral Health Centers, are frequently the sole provider in a geographic area of certain intensive services that are the most effective services for people with disabilities.

We have some concerns that the proposed standard that issuers are required to offer contracts to at least one ECP in each of the proposed ECP categories does not go far enough to include ECP in provider networks. As discussed above, ECPs have substantial experience providing services to individuals with disabilities, experience in some cases that other providers do not have. Allowing issuers to satisfy their obligations under the ACA by contracting with only one ECP in each category seems limited, especially the Hospitals and the Other ECP Provider category which includes an extensive list of ECPs with experience serving people with a range of disabilities.

The providers that HHS has included under the “Hospitals” and “Other ECP Providers” categories are not substitutes for one another. For example, children with disabilities disproportionately rely on Children’s Hospitals. These centers serve as regional hubs and provide services to children that no other hospital in the region can provide. According to the Children’s Hospital Association, children’s’ hospitals are less than 5% of all hospitals but account for 45% of all pediatric inpatient days.<sup>12</sup> However, the proposed rule only requires that Children’s Hospitals be covered as one of the options under the “Hospital” category of ECPs. Children in need of a Children’s Hospital cannot be well served in a Free-standing Cancer Center; just as adults cannot be well served in a Children’s Hospital.

We propose further breaking-out the major ECP categories to better ensure that plans meet the needs of people with disabilities. Ideally, QHPs should be required to contract with all ECPs, as Congress intended. *At a minimum, we reiterate our suggestion from our February 25, 2014 comments on the 2015 Letter to Issuers that HHS should establish separate categories of ECPs to meet the needs of people with disabilities, including children with disabilities.*<sup>13</sup> We believe that children’s hospitals merit designation as a separate ECP category, since many children with complex medical needs or disabilities can get critical services only at a Children’s Hospital. In addition, some of the other types of ECPs currently in the “other ECP” category might merit their own separate categories to ensure that the needs of all enrollees are met. For example, under the current and proposed requirements, Hemophilia Treatment Centers (HTCs) could be excluded from a QHP’s network, even though the majority of those with this diagnosis receive some treatment from HTCs. Likewise, community mental health providers, including Community Mental Health Centers, merit a separate category to ensure sufficient access to these experienced mental health providers.

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<sup>12</sup> Children’s Hospital Association, Strengthening Essential Community Provider Standards to Enhance Access to Pediatric Care, July 2014: [http://www.naic.org/documents/committees\\_b\\_rftf\\_namr\\_sg\\_related\\_cha.pdf](http://www.naic.org/documents/committees_b_rftf_namr_sg_related_cha.pdf)

<sup>13</sup> Consortium for Citizens with Disabilities Comments Regarding Letter to Issuers on Federally Facilitated and State Partnership Exchanges, February 2014: [http://www.c-c-d.org/fichiers/letter\\_to\\_issuers\\_for\\_taskforce.pdf](http://www.c-c-d.org/fichiers/letter_to_issuers_for_taskforce.pdf)

## Quality Improvement Strategy - §156.1130

CCD supports HHS's efforts to align quality improvement standards that align with the National Quality Strategy and HHS Quality Strategy. On the framework outlined in the preamble we have two comments.<sup>14</sup> On point one, QHP issuer's QIS should focus on more than one of the topics outlined in section 1311(g)(1) of the ACA; we recommend at least three areas be included. On point 5, we strongly support the provision that QIS standards should be developed in a public, accessible, and transparent manner that seeks stakeholder feedback.

The preamble notes that HHS does not currently intend to require specific performance measures to be included in a QIS. CCD recommends that HHS require the performance measures endorsed by the National Quality Forum in the five areas listed in the preamble. The National Quality Forum uses a multi-stakeholder process laid out in the ACA to endorse measures for use across the federal government, and is a natural entity to provide quality measures for use across exchanges. In areas where NQF has not endorsed measures, HHS should require other widely accepted measures with a standardized method for collecting and reporting data. We also encourage HHS to standardize the quality data collection (rather than "in a manner and time frame specified by the Exchange" as proposed) to ease data collection, comparisons, and research across exchanges.

Finally, HHS specifically requests comment on whether certain types of QHPs should be excluded from QIS certification requirement. We believe all plans should be required to participate in QIS.

We thank you for this opportunity to comment and welcome your questions or feedback to any of the Health Task Force Co-Chairs

Sincerely,

Consortium for Citizens with Disabilities, Health Task Force Co-Chairs:

Mary Andrus, Easter Seals

Lisa Ekman, Health & Disability Advocates

Rachel Patterson, Association of University Centers on Disabilities

Peter Thomas, Brain Injury Association of America

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<sup>14</sup> See *Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2016*, proposed rule, Vol. 79, No. 228 of the Federal Register at p. 70735.