



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

October 31, 2011

The Honorable Kathleen Sebelius
Department of Health & Human Services
200 Independence Avenue,
Washington, DC 20201

RE: CMS – 9989-P Patient Protection and Affordable Care Act; Establishment of Exchanges and Qualified Health Plans

Dear Madam Secretary:

The Consortium for Citizens with Disabilities (CCD) Health Task Force appreciates this opportunity to provide comments on proposed rules regarding the Establishment of Exchanges and Qualified Health Plans (76 Federal Register 41866, July 15, 2011).

The CCD is a coalition of national consumer, service provider, and professional organizations which advocate on behalf of persons with disabilities and chronic conditions and their families. CCD member organizations' developed 'Principles for Health Care Reform from a Disability Perspective' (attached) to inform their assessment of reform proposals, and continues to use these as our basis for evaluating proposed rules for the implementation of the Affordable Care Act. The CCD Health Task Force is working to ensure that the ACA's implementation achieves access to high quality, comprehensive, affordable health care for all Americans, including people with disabilities and chronic conditions.

In sum, CCD recommends the final rule should:

- Establish national standards that will serve as a minimum level of protection for network adequacy across the country;
- Require access to community-based providers, including non-profit providers, with a documented experience in serving persons with disabilities;
- Require access to community-based providers defined in Section 340 (B) (a) (4) of the Public Health Service Act, as required by Section 1311 (c) (1) (C) of the Affordable Care Act (ACA). Community-based non-profit disability providers should be considered essential, whenever a person with disability is involved. The Essential Community Provider section should specify: "Non-profit, state or county mental health or substance abuse organizations that are licensed or certified by the State."
- Require geographic access, so persons with disabilities are not burdened with great travelling distances;
- Require access to disability-specific specialists;

- Require enrollee choice – each health exchange and qualified health plan (QHP) enrollee should have a choice of primary and specialized provider;
- Require access-nondiscrimination-accommodation – all exchange and QHP providers must fully comply with the Americans with Disabilities Act (ADA) and related civil rights requirements to ensure that persons with disabilities are appropriately served with respect and dignity and facilities and programs are accessible to people with disabilities;
- Be consistent with other HHS and ACA initiatives such as money follows the individual, home and community-based expansions, and person-centered medical/health home;
- Adopt the NAIC (National Association of Insurance Commissioners) Managed Care Plan Network Adequacy Model Act as the minimum national network adequacy requirements for QHP certification and add provisions to require QHPs that are health indemnity plans to demonstrate that they have a sufficient choice of providers accepting their health plan to meet the minimum national network adequacy standards.

• Approval Standards, 155.105 – Partnership Model

With the partnership concept, HHS appears to be contemplating a continuum of state-federal relationships that might exist for development and leadership of an Exchange.

Consumers must be able to obtain eligibility determinations for the appropriate coverage program (whether Medicaid, Exchange premium tax credits and cost-sharing reductions, Basic Health, or other programs), to obtain comparative information on health plans, and enroll in a health plan in a single visit to the Exchange, whether in person, by telephone or on-line. We see serious potential problems if states are able to leave the eligibility and enrollment functions of the Exchange to the federal government under the partnership approach. The state would continue to determine eligibility for its Medicaid program for those not eligible to enroll at the exchange and for others who seek coverage directly at the state, and it is likely that people moving between Medicaid and the Exchange would experience difficulties or gaps in coverage if a different entity (the federal government) were to be in charge of eligibility determinations for those seeking coverage at the Exchange. Such gaps and difficulties would violate the requirement that eligibility be seamless and coordinated between the Exchange and Medicaid. Thus, if HHS decides to operate the eligibility and enrollment functions of the Exchange while states perform other Exchange functions, HHS must ensure this separation is entirely invisible to and seamless for the consumer. We think this would be extremely difficult, but if it is allowed the state must explicitly agree that it will take all necessary actions to work with the HHS to ensure a seamless system, including accepting eligibility determinations for Medicaid made by the federal government.

Whenever functions are contracted out, it is essential that an exchange operated under a Partnership remains accountable for compliance with the ACA and for the performance of its contractors and that this responsibility includes monitoring, oversight and enforcement of the contractual obligations. The ACA and the proposed rule authorize Exchanges to contract out responsibilities of the Exchange with (1) entities incorporated under and subject to the laws of one or more states, that have demonstrated experience in health insurance markets and coverage, and that are not health insurance issuers or treated as health insurance issuers, and (2) the state Medicaid agency. Some functions of the Exchange should not be contracted out to a non-governmental third party because they are inherently governmental. These include eligibility determination for Medicaid and

the premium tax credits for QHPs, as well as appeals processes for eligibility determinations.

Stakeholder Consultation - 155.130

We appreciate the preamble's explicit recommendation for consultation with individuals with disabilities and advocates for persons with disabilities [§155.130(a) and (c)]. Consultation with consumers (and groups that advocate on behalf of consumers) should reflect the diversity of the disability community and a variety of challenges people may face interacting with the exchange. This should include people living with physical, sensory, behavioral, mental and/or cognitive challenges or combinations of them, as well as individuals with chronic diseases or conditions who have frequent contact with the health care system and ongoing health care needs. The Exchange would benefit from consultation, in particular, with experts that can help the Exchange comply with and meet the intent of the Americans with Disabilities Act and Section 508 of the Rehabilitation Act.

In general, exchanges should consult with a panoply of health care interests, and the proposed regulation includes certain entities that must, at a minimum, be consulted. At least two other entities should be added to the list of stakeholders consulted. First, Navigators are an important source of information and will be able to report to the Exchange common barriers to enrollment or areas of consumer confusion. Second, consultation with consumer entities with expertise in low-income tax policy would be beneficial to exchanges. Appropriate entities may be non-profit organizations or IRS-funded Voluntary Income Tax Assistance (VITA) programs. These organizations have specialized knowledge of tax issues for low-income and underserved populations and may have useful advice for communicating important information about premium tax credits.

Required Consumer Assistance Tools and Programs - 155.205

The overarching goal for exchanges is to facilitate consumer access to quality insurance options and intelligently harness market forces to provide the highest possible value to consumers. Consumer assistance is integral to these goals, and the needs of people living with disability or chronic illness must be taken into account when developing and maintaining them. We urge that disability be viewed as a litmus test for all consumers of exchange products and services. If consumers with special needs cannot navigate the exchange, either on-their-own (via the website or kiosks) or via exchange- provided "assistors" (call center, other) or with the help of "outside" assistors, then the exchange is unlikely to realize its key policy objectives.

Section 155.205 outlines the minimum consumer assistance tools and activities that exchanges must provide. However, this "tools and activities" list must be augmented with a needs assessment and with measurable, auditable standards regarding the performance of the customer service activities. Consultation with state developmental disability and mental health counsels on the assessments they currently conduct as required by federal law can provide examples, data and lessons on methodology.

Each state should be required to outline in its Exchange Plan the steps it has taken to conduct an accessibility assessment within the service; the range of consumer assistance tools and programs that it will use in light of those needs (including required tools); and a

mechanism for evaluating the effectiveness of its consumer assistance efforts for people with disabilities.

Navigator Program Standards 155.210

We strongly support the provision in 155.210(b)(2) that requires an exchange to include at least two different types of eligible entities in its Navigator program. This provision is essential to ensuring that Navigator programs meet the needs of diverse populations, including persons living with a disability, chronic illness or special need.

We recommend that at least one type of navigator entity be required to demonstrate a proven track record of serving individuals with a wide variety of disabilities and their families. Medicaid and CHIP administrative matching funds could and should be utilized to target un-insured and under-insured persons with disabilities for such customized navigator services. Entities already familiar with the special needs of people with disabilities are most likely to produce the desired results of navigator programs and exchanges.

Duties of a Navigator, §155.210 (d)

Section 155.210(d)(1) states that it is a duty of a Navigator to maintain expertise in “eligibility, enrollment, and program specifications.” We recommend that the rules specify that this requirement includes expertise regarding Medicaid, CHIP, Basic Health (if applicable), and other state-funded coverage programs for which Navigator clients may be eligible. Since individuals will transition between eligibility for different coverage programs, it is critical that Navigators have a comprehensive understanding of all coverage options (private or public) in an exchange’s service area. Without such comprehensive knowledge, Navigators will be unable to direct consumers to the best coverage option for them. To help ensure that Navigators provide information in a fair, accurate and impartial manner and to prevent fraud and abuse, Navigators should be required to ensure that all staff performing Navigator duties are appropriately certified, maintain certification and are capable of carrying out their duties. Staff must be provided with initial accessibility and program training and their work should be monitored on an ongoing basis.

Section 155.210(d)(5) requires Navigators to provide information in a manner that is appropriate to individuals with disabilities. To ensure that individuals with disabilities can obtain adequate assistance, Navigator programs should have appropriate materials available based on the need.

General Standards for Exchange Notices – 155.230

We appreciate CMS’s recognition in the preamble and proposed regulatory language that applications, forms, and notices must be provided in plain language and provide meaningful access to persons with disabilities. Communications geared toward persons with disabilities is not only desirable but required by various laws, including Section 2001 of the ACA (enacting Public Health Service Act § 2719, which requires group health plans and health insurance issuers to provide notice of appeal processes in a “culturally and linguistically appropriate manner”); Title VI -- 42 U.S.C. § 2000d, et seq.; ACA, Section 1557, 42 U.S.C. § 18116 (Nondiscrimination).

In the Preamble, CMS states that there are a number of ways by which an Exchange may provide access to persons with disabilities and suggests several, specifically information about the availability of oral interpretation services, information about languages in which written materials are available, and the availability of different formats for persons with disabilities. CMS seeks comment as to whether the examples should be codified. We strongly support inclusion in the final rule of, at a minimum, these suggestions to assure effective communication.

We further recommend a requirement that HHS approve the accessibility policies for the Exchange document. HHS should also ensure that the Exchanges provide an opportunity for stakeholders to review notices for readability and accessibility.

Privacy and security of information 155.260

Ensuring that consumers' personal information is kept private and secure is an important element of fostering the public's trust of new insurance exchanges. Because people with disabilities or chronic illnesses use a disproportionate amount of health services, we support the application of privacy protections to the collection, use, and disclosure of personally identifiable information. Additionally, we support a requirement for exchanges to establish privacy and security standards that are transparent, publically available and made clear to all potential beneficiaries.

To achieve this level of protection, we recommend the following:

- Require exchanges to follow the full complement of Fair Information Practice Principles (FIPPs). Ensure that Exchange privacy policies are subject to public notice and comment prior to submission to the HHS Secretary. An exchange's specific policies should be part of a state-operated Exchange's written Exchange Plan and (in the case of a federally facilitated exchange) a similar comparable document that is available to the public.
- Adopt language in the final regulation that incorporates the strict limitations in the statute on the ability of Exchanges to collect, use and disclose personally identifiable information. Restrict the collection, use and disclosure of social security numbers for any purpose unrelated to eligibility determination. Ensure Exchanges do not collect data on individuals who are merely exploring the Exchange website for information and not applying for coverage.
- Make clear in the final rule that even those Exchanges that are covered by the HIPAA Privacy Rule are subject to any specific privacy rules set by HHS or states governing Exchanges. Require Exchanges to follow the "individual rights" provisions of the HIPAA privacy rule or to incorporate these provisions into their policies. Require Exchanges to obtain specific authorization from individuals prior to using any personally identifiable information (including an IP address) for a marketing purpose.
- Retain the requirements applying privacy and security standards to Exchange contractors and apply these requirements to the Navigator program as well.
- Establish a tiered penalty structure, so that civil penalties apply to relatively lesser violations of privacy and security requirements and criminal penalties apply when there is a knowing or willful violation. Require Exchanges to take action against contractors that violate privacy or security standards.

Single Streamlined Application 155.405

A single, streamlined application and application process is central to the success of the No Wrong Door concept. An applicant should only be required go through the application process once in order to receive an eligibility determination for all insurance affordability programs. Applications should be accessible to a variety of audiences, including people with disabilities.

The regulation should clarify that the single streamlined application must be accessible for people with disabilities. Given that a large proportion of applicants will likely obtain assistance completing and submitting their application, we support the provision at paragraph (c) that exchanges accept applications from multiple sources and via multiple mechanisms. In addition to accepting applications online, over the phone, and via mail/fax, exchanges should also accept in-person applications (consistent with section 1413(b)(1)(A)(ii) of the ACA). These in-person applications might be submitted to a Medicaid eligibility office or an Exchange office. Additionally, the regulation should clarify that online applications may also include applications available via mobile devices. Regardless of the method of application, however, all applicants should be able to obtain assistance with the application and enrollment process that is culturally and linguistically appropriate from an unbiased and knowledgeable source.

The ACA permits states to use alternative forms to the single streamlined application, but these must be approved by HHS. As the regulation suggests, the HHS should have a process in place to approve alternative forms initially and to approve any subsequent changes made to the form. HHS should issue standards for the development of alternative forms and establish a process to approve such forms initially and on an ongoing basis. The Exchange should be required to obtain approval for any changes to the form(s) on an ongoing basis.

Initial and Annual Open Enrollment Periods 155.420

We recognize the need to establish defined enrollment periods starting in 2014 when insurers will be required to provide health coverage to individuals seeking it. The experiences of CCD members and their constituents with initial and annual enrollment periods for Medicare prescription drug plans in particular illustrate the importance of outreach and education about enrollment periods and their consequences. First-time enrollees in particular will need considerable time to learn about health insurance in general and their individual options in particular. Reminders about the opportunity to evaluate coverage needs and seek the most appropriate coverage for them are especially important messages for people with complex health care needs. We strongly urge that reminders about upcoming annual enrollment periods be required and designed with consumer input.

Special Enrollment Periods 155.420

Generally, special enrollees will be entitled to enrollment the first day of the month following QHP selection. However, under the proposed rules, special enrollees who select a QHP after the 22nd of a month may have to wait until the first day of the second following month for their enrollments to be effective. The rules appropriately make exceptions for newborns and adoptions to ensure that children will have immediate coverage. However, we are concerned that the timing will still leave some other people with gaps in coverage. For example, if someone suddenly loses a job that provided

coverage and has no immediate access to COBRA, they could be without coverage from the 23 of one month until the first day of the second following month.

Further, a person losing Medicaid or CHIP could be subject to an enrollment delay under the proposed rules. This is inconsistent with the statutory goal of seamless eligibility and enrollment, and could cause grave problems for a low income person in the midst of a course of treatment. Medicaid programs are now designed to provide retroactive coverage to applicants, at least to the first day of the month of the application, and exchanges should similarly be able to implement continuous coverage systems. Several years ago, HHS contracted with a third party to provide temporary drug coverage to low income Medicare Part D beneficiaries until enrollment glitches could be resolved. HHS should design a fallback enrollment system to ensure that people losing Medicaid or CHIP coverage will not experience any gaps in their coverage until their coverage under the Exchange becomes effective. Exchanges should be required to allow new and special enrollees to print out temporary identification that would verify to providers that the plan would retroactively pay the claim once plan enrollment is processed.

Final rules should clarify that a person losing any source of minimum essential coverage is entitled to special enrollment, even if they had multiple coverage sources previously. (The ACA defines minimum essential coverage as Medicaid, Medicare Part A, CHIP, TRICARE, VA Health, Peace Corps health plans, eligible employer-sponsored plans, individual market plans, grandfathered plans, or other coverage such as a high risk pool, as long as the coverage does not consist only of essential benefits.)

The rules should also make loss of an employer's contributions to employment-based coverage a qualifying event; clarify that the definition of dependent includes dependents under state law or the plan rules and that marriage and civil unions are treated as special events. They should clarify that the date the exchange completes an eligibility determination for premium or cost sharing credits begins the special enrollment period for someone qualifying that way. Further, people with disabilities who are on COBRA should be able to select a qualified health plan (QHP) when their premiums rise to 150% of standard rates (the disability extension). This is a time when a QHP may be more affordable than COBRA.

Transparency in Coverage 155.1040 and 156.220

The regulation places complementary requirements on Exchanges and QHP issuers regarding the disclosure of key information, in plain language, to Exchanges, HHS, State Insurance Commissioners and the public. We strongly support the codification of the important transparency protections in the proposed rule. The required information will help consumers with disabilities pick coverage that best meets their needs.

The proposed rule requires Exchanges to determine whether the transparency in coverage measures are provided in plain language. HHS should establish an enforcement process for the plain language requirement. HHS and DOL should work with individuals and organizations with expertise in plain language writing and language and disability access, as well as use lessons learned from NAIC's work developing recommendations for a template summary of benefit and coverage document.

The proposed rule requires Exchanges to monitor whether a QHP issuer has made the amount of enrollee cost-sharing under the individual policy with respect to a specific item or service provided by a participating provider available in a timely manner upon the

request of an individual. HHS should provide guidance on how an Exchange will monitor compliance with this requirement. In particular, Exchanges should clearly state on the Exchange website that consumers can request this information from QHPs and provide appropriate contact information. In addition, HHS should allow Exchanges to institute financial penalties for non-compliance.

The proposed rule requires QHP issuers to provide the following information:

- (1) Claims payment policies and practices
- (2) Periodic financial disclosures
- (3) Data on enrollment
- (4) Data on disenrollment
- (5) Data on the number of claims that are denied
- (6) Data on rating practices
- (7) Information on cost-sharing and payments with respect to any out-of-network coverage
- (8) Information on enrollee rights under Title I of the ACA

We support the codification of all the statutory categories.

QHP issuers should be subject to an enforcement process for the plain language requirement. In drafting guidance on best practices for plain language writing, HHS and DOL should work with individuals and organizations with expertise in plain language writing and language and disability access, as well as use lessons learned from NAIC's work developing recommendations for a template summary of benefit and coverage document.

HHS should require QHPs to provide information about cost-sharing with respect to a specific item or service provided by a participating provider, as well as all of the transparency in coverage measures outlined under §156.220(a), to individuals free of charge upon request. This information should be provided as soon as practicable but no later than seven days following the request. QHPs should enable consumers to make this request online, but also by phone, fax, or mail. The consumer should also be able to choose how they would prefer to receive the information, with a paper option always available.

Establishment of Exchange Network Adequacy Standards 155.1050;

Qualified Health Plan Network Adequacy Standards 156.230

Essential Community Providers 156.235

The requirements of network adequacy and essential community providers are fundamental to ensuring that persons with disabilities receive all health related benefits

that they require, in a timely, convenient, and appropriate delivery of services. Several principles are important to CCD's approach to these topics. These are:

1. Access to community-based providers, including non-profit providers, with a documented experience in serving persons with disabilities;
2. Access to community-based providers defined in Section 340 (B) (a) (4) of the Public Health Service Act, as required by Section 1311 (c)(1) (C) of the Affordable Care Act (ACA);
3. Geographic access, so persons with disabilities are not burdened with great traveling distances;
4. Access to disability-specific specialists and services;
5. Choice – each health exchange and qualified health plan (QHP) enrollee should have a choice of primary and specialized provider.
6. Access—non-discrimination accommodation – all exchange and AQHP providers must fully comply with the Americans with Disabilities Act (ACT) and related civil rights requirements to ensure that persons with disabilities are appropriately served with respect and dignity and access to adequate accessible facilities and programs;
7. Consistency with other HHS and ACA initiatives such as money follows the individual, home and community-based expansions, and person-centered medical/health home.

The ACA requires the HHS Secretary to establish network adequacy requirements for health insurance issuers seeking certification of QHPs. However, the rule proposes to delegate this responsibility to each Exchange. We believe that the final rule should establish national standards that will serve as a minimum level of protection for network adequacy across the country. Such standards can be broad enough to ensure that they are appropriate to each state's needs. The law requires all QHPs -- which will include both managed care plans and health indemnity plans -- to meet the minimum national network adequacy standards.

We support the proposed additional requirement that the Exchange establish specific standards under which QHP issuers would be required to maintain the following:

- (1) sufficient numbers and types of providers to assure that services are accessible without unreasonable delay;
- (2) arrangements to ensure a reasonable proximity of participating providers to the residence or workplace of enrollees, including a reasonable proximity and accessibility of providers accepting new patients;
- (3) an ongoing monitoring process to ensure sufficiency of the network for enrollees; and
- (4) a process to ensure that an enrollee can obtain a covered benefit from an out-of-network provider at no additional cost if no network provider is accessible for that benefit in a timely manner.

The preamble seeks comment on an additional standard that would require exchanges to "Ensure that QHPs' provider networks provide sufficient access to care for all enrollees, including those in medically underserved areas." The proposed standard would require a provider network to ensure "reasonable access to care for all enrollees enrolled through the Exchange, regardless of an enrollee's medical condition." We support the adoption

of this standard, which will ensure that consumers in isolated geographic areas, regardless of health status, are able to access needed care. Under this standard, QHPs should also be required to address the elements previously identified in the CCD principles above.

Access to QHP directories:

When determining how best to make provider directories available to enrollees and potential enrollees, it is important to reiterate that Exchanges are required to comply with Title VI of the Civil Rights Act, Section 508 of the Rehabilitation Act, and Section 1557 of the ACA. As such, they should be required to ensure that information is available in a variety of ways and formats to meet the needs of enrollees and potential enrollees with disabilities.

Thank you for this opportunity to comment, and welcome your questions or feedback to any of the following Task Force Co-Chairs, Julie Ward, The Arc, (ward@tharc.org) or Peter Thomas, National Association for the Advancement of Orthotics and Prosthetics, (Peter.Thomas@PPSV.COM)

On behalf of:

American Association on Health and Disability

American Network of Community Options and Resources

American Occupational Therapy Association

American-Speech-Language-Hearing Association

Association of University Centers on Disabilities

Bazelon Center for Mental Health Law

Easter Seals

Epilepsy Foundation

Family Voices

Mental Health America

National Alliance on Mental Illness

National Association for the Advancement of Orthotics and Prosthetics

National Association of County Behavioral Health and Developmental Disability Directors

National Council on Independent Living

National Disability Rights Network

National Down Syndrome Congress

National Multiple Sclerosis Society

Paralyzed Veterans of America

The Arc of the United States

United Cerebral Palsy

United Spinal Association