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1973-2013

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VIA ELECTRONIC SUBMISSION

Centers for Medicare & Medicaid Services
Department of Health and Human Services
P.O. Box 8016
Baltimore, MD 21244-8016

Attention: CMS-2324-P
Medicaid, Children's Health Insurance Programs, and Exchanges: Essential Health Benefits in Alternative Benefit Plans, Eligibility Notices, Fair Hearing and Appeal Processes for Medicaid and Exchange Eligibility Appeals and Other Provisions Related to Eligibility and Enrollment for Exchanges, Medicaid and CHIP, and Medicaid Premiums and Cost Sharing

Dear Sir/Madam:

The Consortium for Citizens with Disabilities (CCD) is pleased to provide these comments on behalf of the CCD Health and Long-Term Services and Support Task Forces on the proposed regulations entitled Medicaid, Children's Health Insurance Programs, and Exchanges: Essential Health Benefits in Alternative Benefit Plans, Eligibility Notices, Fair Hearing and Appeal Processes for Medicaid and Exchange Eligibility Appeals and Other Provisions Related to Eligibility and Enrollment for Exchanges, Medicaid and CHIP, and Medicaid Premiums and Cost Sharing published in the Federal Register on January 22 (CMS-2334-P).

CCD has serious concerns regarding several key aspects of the intended approach to defining an Alternative Benefit Plan (ABP) as outlined in these proposed regulations. We believe there must be more transparency in the ABP process and that consumers and other stakeholders, including people with disabilities and their representatives, must be given additional notice of a state's plan to submit a state plan amendment to create an ABP or make changes to existing ABPs. The existing provisions do not provide sufficient time for thoughtful review and stakeholder input prior to submission of the state plan amendment request to HHS and CCD urges HHS to reconsider this approach.

CCD also believes additional provisions need to be added regarding ensuring that the level of benefits provided in each of the EHB categories are adequate to meet the needs of individuals and the benefits themselves are meaningful. In particular, CCD is disappointed to see that HHS has chosen not to provide states any guidance regarding the habilitation benefit in ABP. CCD urges HHS to reconsider its approach toward the habilitation benefit and supports a federal definition of habilitation services for ABP.

CCD is also concerned about how people who qualify for exemption from mandatory enrollment in a benchmark plan will be identified and urges HHS to include additional details regarding how this will be accomplished. Finally, CCD believes that additional provisions are necessary to ensure that the design and implementation of ABPs do not discriminate against people with disabilities and chronic health conditions.

CCD also has significant concerns regarding the changes to cost-sharing rules proposed in this rule. CCD believes that the proposed changes will cause many people with disabilities or multiple chronic conditions, especially people with mental illness, to forgo needed care or prescriptions due to the inability to pay. Although each of the proposed changes on their own might appear small and innocuous, CCD believes the cumulative effect of the different cost-sharing provisions could be devastating when they are all added together for people already living in poverty and making difficult economic choices. CCD urges HHS to reconsider the approach to cost-sharing outlined in the NPRM as discussed below.

I. Alternative Benefit Plans and Essential Health Benefits in the Medicaid Expansion Group

CCD is aware that these regulations adapt the §1937 procedures for establishing benchmark plans in Medicaid and does not recommend changing that overall approach. In particular, CCD supports the decision to allow states flexibility to add benefits to an ABP over and above the benefits offered in the benchmark option selected. CCD also commends HHS for allowing states to include all state plan services in an ABP for the expansion group, regardless of whether they are offered in the state plan for other populations. In particular, CCD is pleased that HHS has specifically listed services that can be vital to people with disabilities and chronic health conditions as allowable in benchmark equivalent (42 CFR §440.335 (c)(1)) and Secretary-approved coverage (42 CFR §440.330(d)) ABPs, including; home and community based services under 1915(i), self-directed personal assistance services under 1915(j), and home and community based attendant services and supports through 1915(k).

However, the undersigned groups have the following concerns regarding specific aspects of the proposed rule.

Adequacy of benefits within EHB categories (42 CFR §440.347):

CCD is concerned that there is no requirement regarding the adequacy of benefits within each EHB category in the proposed regulations. While CCD appreciates that the existing regulations require that the coverage offered through an ABP to the expansion group must be equal to the coverage in the benchmark with no ability to substitute or remove benefits within a benchmark (42 CFR §440.330), there is no requirement in the draft rule to ensure that the benefits within that plan are adequate to meet the needs of people. In addition, there is no language with respect to what it means to cover an EHB category other than that the ABP must contain EHB coverage, including benefits within each of the 10 categories (42 CFR §440.347). Based on this language it would seem that coverage of one benefit, even if that benefit were of insufficient scope and duration to provide adequate services to meet an individual's needs, would satisfy the requirement to provide EHB.

CCD recommends that at a minimum, HHS provide a specific cross-reference to 42 CFR §440.230(b) and state explicitly that the requirement that every service offered through the Medicaid state plan "be sufficient in amount, duration, and scope to reasonably achieve its purpose," applies to the requirement to provide EHB in the ABPs. CCD also recommends that the regulations be revised to require states to supplement the benefits contained in a benchmark if any service contained within an EHB category is not sufficient in amount, duration, or scope to reasonably achieve its purpose. In addition, CCD urges

HHS to adopt the anti-discrimination provisions discussed below to ensure that there is adequate coverage within each EHB category within the ABPs.

Populations exempt from mandatory enrollment in a benchmark plan (42 CFR §440.315):

CCD is pleased that the proposed rule clarifies the populations that are exempted from mandatory enrollment in an ABP. In particular, CCD commends CMS for the clarification and expansion of the medically frail definition in 42 CFR §440.315. The importance of ensuring that people with disabilities, medically frail individuals and other individuals exempt from mandatory enrollment have the ability to access the full state plan Medicaid benefit package if the services offered in the ABP are insufficient cannot be overstated. CCD is supportive of the application of these exemptions and the approach taken in the proposed rule.

However, CCD is concerned about how people will be identified as meeting the criteria for being medically frail or needing long-term services and supports (or any other basis for exemption) and therefore exempt from mandatory enrollment in a benchmark plan. CCD recommends adding a requirement that the notice provided to individuals who have been found eligible for the expansion group include detailed information regarding how one can qualify for an exemption and the services and supports that would be available to a person who is exempt that are not available in the ABP. This requirement ought to be added to the requirements at 42 CFR §435.917 (b)(1). Notice should include information regarding how to request and receive an exemption.

Nondiscrimination (42 CFR §440.347(e)):

CCD appreciates the inclusion of a non-discrimination mandate in § 440.347(e) (“Essential health benefits cannot be based on a benefit design or implementation of a benefit design that discriminates on the basis of an individual’s age, expected length of life, an individual’s present or predicted disability, degree of medical dependency, or quality of life or other health condition.”) However, to ensure that the non-discrimination requirements for Medicaid populations are no less robust than the non-discrimination requirements articulated for provision of EHB in the private insurance realm, we urge HHS to explicitly include the other non-discrimination mandates that attach to the private insurance EHB requirements:

- EHB must “reflect an appropriate balance among the categories” (ACA, § 1302(b)(4)(A));
- The Secretary may “not make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of their age, disability, or expected length of life” (ACA, § 1302(b)(4)(B));
- EHB must “take into account the health care needs of diverse segments of the population, including women, children, [and] persons with disabilities” (§ 1302(b)(4)(C)).

Taken together, these protections ensure that people with disabilities and other vulnerable populations are protected from plan designs that systematically bar access to medically necessary care and treatment services through service exclusions and limits, utilization management techniques, and cost-sharing.

In addition to taking the steps above, HHS should prohibit ABPs from including:

- Participant cost-sharing designs that are more burdensome on some benefits than others;
- Unreasonable and arbitrary visit and dollar limits on a specific category of benefits, so as to discourage participation by individuals with certain conditions or disabilities; and
- Targeted use of utilization management techniques for some benefits, and not others; and
- Mental health benefits that are subject to higher limitations on amount, scope, and duration than benefits intended for physical/medical conditions, or narrowly specifying that mental health services cannot be a component of other EHB categories, such as the mental health rehabilitation needs that will follow a traumatic medical event.
- Defining the benefits in such a way to exclude coverage for those services based upon age, disability, expected length of life, or the willingness or capacity to participate in wellness programs or behavioral incentive programs.

Finally, in developing analyses to assist federal and state regulators in identifying discriminatory practices and ensuring compliance with the non-discrimination provisions, we urge HHS to explicitly define how the following criteria should be developed and implemented by the states and how they will be monitored and enforced by HHS:

- Medical necessity requirements for Medicaid must be evaluated and standardized, and HHS should monitor state implementation of medical necessity to ensure that people with disabilities and other chronic and complex conditions have unimpeded access to essential care and treatment.
- Utilization management techniques, exclusions, and service limits must be closely monitored to ensure that plans have not put in place barriers to services or excluded or limited certain items or services solely to deny access to care for people with disabilities and chronic and complex health conditions. We urge HHS to develop a list of practices that amount to discrimination to help guide monitoring and enforcement activities. For instance, a monthly limit on prescription drugs (e.g., several states have monthly limits of three or four prescription drugs) is also per-se discriminatory, as applied to people with disabilities and other chronic conditions.
- Ongoing procedures for states to monitor and share data on how they are meeting their benefit design and implementation anti-discrimination obligations over time, and make this information transparently and readily available in at least an aggregate fashion to HHS, the public, and to health advocates.

Habilitation Standards for Alternative Benchmark Plans

In its proposed rule for EHB for exchanges, HHS proposed that issuers be able to determine coverage for habilitative benefits absent a state definition. CCD strongly objects to issuer-defined EHBs and we

appreciate that HHS omitted this option in the Medicaid benefits regulation. As CCD has stated in previous comments for EHB in the exchanges, our strong preference is for a federal standard for the habilitative benefit within ABPs. Toward that end, we recommend HHS incorporate a minimum model habilitative benefit into § 440.347(d) for adoption by states.

For a definition, HHS should consider Medicaid's long history with habilitation, as well as the National Association of Insurance Commissioners' (NAIC) definition of habilitative services: "health care services that help a person keep, learn, or improve skills and functioning for daily living. Examples include therapy for a child who isn't walking or talking at the expected age. These services may include physical and occupational therapy, speech-language pathology and other services for people with disabilities in a variety of inpatient and/or outpatient settings" (NAIC Glossary of Terms for the ACA).

Since HHS has incorporated the NAIC definition into glossary and explanation documents for the exchanges, the NAIC definition should provide some consistency between exchange coverage and ABP coverage.

In its model definition, HHS should include a set of habilitative services specifying the minimum types of services to be provided (e.g., occupational therapy, physical therapy, speech-language therapy), and should specify that these services are a floor. In addition, ABPs must cover habilitative devices, such as durable medical equipment (e.g., wheelchairs), orthotics, prosthetics, low vision aids, hearing aids, augmentative communication devices that aid in hearing and speech, and other assistive technologies and supplies.

Minimum Parameters for Habilitative Coverage:

HHS should require that when states adopt and develop a habilitative benefit for the ABP, that they follow the listed parameters:

- Cover habilitation separate and distinct from rehabilitation. For example, the plan cannot substitute rehabilitation for habilitation or apply only a single visit limit to both benefits.¹ Each benefit must have separate and distinct visit limits which are applied based upon medical necessity, not based upon an arbitrary cap;²
- Cover habilitative services without age restrictions – a pediatric only habilitative benefit is inadequate, especially as the new eligibility category is for adults only;

¹ Numerous states appear to have base-benchmarks that apply a single, existing rehabilitation visit limit to both the rehabilitation and habilitation benefit. For the majority of states choosing this option, this has meant a 20-visit limit for PT and OT combined whether it is rehabilitation or habilitation. This so severely limits the availability of the therapies it and would discourage enrollment by anyone in need of these medical services.

² Setting distinct limits for habilitation is critical to patients attaining a functional ability for the first time. Coverage of habilitative services and devices without arbitrary limits is especially important for children who may suffer from a condition at birth (such as cerebral palsy, autism or spina bifida) or from an illness or injury, that prevents normal skills development and functioning. Receiving sufficient habilitative services that helps the child *acquire*, improve, or retain a skill or level of functioning that they did not previously possess can mean the difference between talking and not talking, walking and not walking, or needing special education and being able to join a regular classroom. Some children will need habilitative services only for a short time, while others will need them on an ongoing basis to ensure that hard-earned skills are not lost or, in the case of children with cerebral palsy, for example, so their muscles function as well as possible.

- States must evaluate their ABP habilitative benefit separate from coverage in the Exchange; they cannot simply adopt the definition or coverage limits used in the Exchange for Medicaid ABPs.
- Cover habilitation services which *maintain* an individual’s functional status, as defined by the HHS Summary of Benefits and Coverage regulation;
- Not imposing financial requirements (such as copayments or coinsurance), quantitative treatment limitations (such as a limit on the number of outpatient visits or inpatient days covered), or financial limitations (such as annual or lifetime caps on habilitative services and devices that are more restrictive than the predominant requirements or limitations that apply to all other benefit categories;
- Covering habilitative devices without arbitrary restrictions and caps that limit the effectiveness of the benefit;³
- Prohibit the exclusion of specific conditions or diagnosis from accessing the benefit;⁴ and
- Prohibit the use of cost-sharing requirements or utilization management tools which target the habilitation benefit and are not applied to other EHB benefits.

Evaluation of the Coverage of Habilitative Services and Devices:

Given the considerable amount of questions HHS has regarding habilitation, we urge HHS to stipulate in the final regulation an ongoing process for data collection and evaluation related to ABP and exchange coverage of habilitative services and devices. If this experience were compared to the model definition of habilitation, that would give parameters for determining the adequacy of coverage for the first year of ABP and exchange operation.

Notice of ABP State Plan Amendments – 42 CFR §440.386:

CCD is concerned that the notice requirements outlined in this proposed rule regarding the submission of a state plan amendment to establish or modify ABPs are insufficient. Providing sufficient notice and allowing stakeholders the opportunity to comment is essential to ensuring that the ABP meets the needs of the target population that particular ABP is designed to serve.

This proposed rule requires states developing an ABP to have a public notice and comment period of no less than two weeks if the ABP provides coverage that is less than that provided by the state’s approved state plan, includes cost sharing, or modifies an existing ABP by adding benefits or increasing or adding cost-sharing. In addition, this proposed rule requires public notice before implementation of a state plan amendment establishing an ABP with the same or more benefits as the current state plan, reducing cost-sharing, or adding benefits.

³ As they grow, children will need frequent replacements of devices such as wheelchairs, glasses, orthotics and prosthetics, and as their skills develop, they may need new augmentative communications devices. For example, a child who gets a wheelchair or prosthetic limb at age 2 will need new devices as they grow.

⁴ For example, Tennessee appears to be limiting the rehabilitative and habilitative benefit to conditions resulting from an acute disease, injury, autism in children under age 12, or cleft palate. This suggests that individuals with other developmental disabilities such as intellectual disability or cerebral palsy would not be able to access rehabilitation or habilitation services.

CCD is concerned because much of the current oversight framework for EHB and ABPs relies on input from stakeholders to identify inadequate coverage of required EHB categories, or discriminatory benefit design or implementation. Although it was not consistent across states, stakeholders were given an opportunity to review and comment on proposed EHB packages in the private insurance market. At minimum, stakeholders had thirty days to review proposed state benchmark selections when HHS released the proposed EHB rule. Stakeholders should be given at least the same opportunity for review and comment as states develop their Medicaid ABPs. As such, CCD recommends CMS require states follow the same public notice and comment requirements as for Section 1115 waiver applications. This includes a 30-day public notice and comment period, with hearings, before the state submits its application to CMS for approval. In addition, this should include a compliance provision to help ensure meaningful participation by the public.

II. Cost-Sharing Provisions 42 CFR §447.52 et seq

CCD has serious concerns with many of the cost-sharing changes made in this proposal. People with disabilities and chronic conditions have high utilization of outpatient services and prescription drug coverage. Although these cost-sharing proposals might seem like nominal increases, for people living on Supplemental Security Income and others who have income below 100% of the federal poverty level, there really is no such thing as a nominal cost. An increase in cost-sharing of \$10 a week might not appear to be much but this could mean going without a meal (or two) or forgoing a prescription for an individual.

Particularly worrisome to CCD is the potential cumulative effect that the increased cost-sharing across different service categories (outpatient, prescription drugs, the possibility of cost sharing for HCBS) could have on people with disabilities and multiple chronic conditions. Numerous studies have shown that even nominal cost-sharing obligations for this population can deter people from accessing the care and treatment that they need to stay healthy.⁵ For people with complex medical needs, the failure to get any needed care can have a cascading effect on the person's health and result in significant increases in health care cost and utilization in the long run.

Many Medicaid beneficiaries with disabilities have multiple disabilities and health complications that require ongoing therapies, treatments and medical devices in order to live in the community rather than institutional settings.

AC is a young girl with infantile spasms, a severe form of epilepsy, developmental delay, dystonia and is unable to walk, swallow properly or eat. She has been on multiple medications to deal with her seizures, her spasticity, reflux and frequent urinary tract infections. She is receiving occupational, physical, swallowing and speech therapies. The combination of finding the right medications and the therapies has improved her ability to function but she still requires a feeding tube and uses a wheelchair

⁵ See, e.g., S. Artiga & M. O'Malley, "Increasing Premiums and Cost Sharing in Medicaid and SCHIP: Recent State Experiences," Kaiser Commission on Medicaid and the Uninsured (May 2005), available at <http://www.kff.org/medicaid/7322.cfm>; Daniel Hartung et al., Impact of a Medicaid Copayment Policy on Prescription Drug and Health Services Utilization in a Fee-for-Service Medicaid Population, 46 Med. Care 565 (2008) and L. Ku & V. Wachino, "The Effect of Increased Cost Sharing in Medicaid: A Summary of Research Findings," Center on Budget and Policy Priorities (July 7, 2005), available at <http://www.cbpp.org/files/5-31-05health2.pdf>.

for mobility. Medicaid has enabled her family to provide the care and treatment she requires but even minimal increases in cost sharing could jeopardize the progress she is making.

AR is twelve years old, and has Peter's Plus Syndrome, which is a condition that is characterized by developmental delay, eye abnormalities, and short stature. She had bi-lateral corneal transplants as an infant. Medicaid covers her occupational therapy, where she is learning life skills, like how to compensate for her dwarfism and reach for items safely so that when she lives independently, she can do so with accommodations. Medicaid covers weekly physical therapy sessions and surgery to straighten her feet and strengthen her muscles so that she can learn to walk on her whole foot instead of tiptoes. She is constantly at risk of rejecting her cornea transplant, and must have regular eye check-ups. Even minimal changes in cost sharing could place the progress she has made at risk if the family is forced to make difficult choices about the ongoing treatments and medical services she requires to keep her vision and learn the skills she needs to live independently in the community.

CCD is concerned that the proposed cost-sharing changes would be devastating for AC and AR and their families. Combined with the proposed changes to the aggregate cap on cost-sharing discussed below, this could jeopardize their ability to receive needed care and might make it difficult for them to live independently in the community.

Cost-Sharing for Inpatient Services

Although CCD has some significant concerns with some of the cost-sharing proposals, CCD is pleased that HHS is considering changing its approach to cost-sharing for inpatient services. CCD supports changing the co-pay for inpatient services to \$4 for the first day. People are not admitted to facilities for inpatient services without a doctor's determination that such services are medically required. The current cost-sharing is likely deterring some people with disabilities and chronic conditions from getting needed inpatient services, as 50% of the cost of the first day of services could be devastating to people whose incomes are under 100% of the federal poverty line. We encourage HHS to include this change in cost-sharing for inpatient stays in the final rule.

Cost-Sharing for Long-Term Services and Supports

CCD is pleased that the proposed rule provides states with the option of exempting individuals who are required to spend all but a minimal amount of income for personal needs receiving home and community based services from cost sharing in 42 CFR §447.56. Extending this exemption to people receiving services and supports in the community is consistent with and supportive of the efforts to rebalance away from institutions and toward community living as required by the Olmsted decision. CCD is very supportive of any changes made to provide people with disabilities opportunities to live independently in the community and therefore supports this change. CCD recommends that HHS make this exemption mandatory rather than optional for states.

CCD Opposes Cost Sharing for Long-Term Services and Supports

As CMS acknowledges, community-based long term services and supports (LTSS) are different from other outpatient services. Imposing cost sharing on individuals who have life-long disabilities, who need comprehensive, continuously available services and supports in order to live safe and healthy lives, and who are very poor cannot be justified.

Many, if not most, individuals who receive LTSS, live in extreme poverty. All but a meager amount of what little they receive through various public insurance programs is spent on their food and shelter costs. Imposing cost sharing on individuals who receive LTSS, who likely would not be able to meet their obligations, would further reduce payments to providers and could put the individual at risk of unnecessary institutionalization.

LTSS are not provided in finite increments, but are on-going, continuous services. Individualized services and supports that people with significant disabilities need are not incremental in nature nor are they easily broken down into “units” of service or “episodes of care.” LTSS are provided via person centered plans. CMS is to be commended for the leadership position it has staked out in requiring person centered approaches to all parts of the health care system. Through the person centered planning process, services and supports are chosen by a team of health care professionals and the individual and are based on the individual’s need. The planning process protects against overutilization of unnecessary services. Cost sharing could create a barrier to implementing person centered planning and plan development. The individual and the interdisciplinary team might forgo a needed service to avoid incurring excessive cost sharing expenses.

We ask HHS to exempt individuals who are receiving Medicaid-covered home and community based LTSS pursuant to a waiver or plan of care. Care and services for these individuals are already adequately, increasingly heavily, vetted during the process used to establish the plan of care. This planning process protects against overutilization of unnecessary services, rendering cost-sharing unnecessary for this purpose. Furthermore, cost sharing can create significant challenges to the proper execution of the plan of care by driving its development at the expense of individual need. Take, for example, an individual on SSI (\$716/month) who is enrolled in a Medicaid home and community-based waiver program. The person-centered care team has determined that the plan of care should include physical therapy twice a week. Under HHS’ current proposal, this individual would be responsible for payment for \$48.00 in copayment for just the first six weeks for just one service in the plan of care—an expense they would find impossible to meet. Under these circumstances, copayments, rather than patient need, can drive plan development (even with a 5% aggregate cap).

When the substantive cost sharing provisions were first added to the Medicaid Act in the early 1980s, Medicaid coverage of long term community-based care was in its infancy. Now, however, state Medicaid programs across the country have home and community based care options for the elderly, individuals with disabilities, and children with HIV/drug dependence. In many instances, the community setting is a small residential setting where the beneficiary is paying the landlord for room and board, etc. Indeed, many individuals in home and community settings have already been determined to be eligible to retain only limited funds, such as a personal needs allowance or a spousal allowance. For practical purposes, these individuals are financially situated similarly to those in institutional settings. Furthermore, in order to qualify for Medicaid HCBS provided under the most common authorities, such as 1915 (c) Waivers, an individual must meet the state’s institutional level of care—so, for all intents and purposes, the Medicaid HCBS population is the same population as those residing in institutions, and are simply receiving their services and supports in a different setting. Given that both their financial profile and their level of support need are materially similar, individuals receiving services in institutions and in HCBS programs should be afforded the same protections from cost-sharing.

It is also important to note that cost sharing provisions for individuals receiving HCBS could raise Olmstead issues by pricing individuals out of the community and into more restrictive settings. The risk of violating an individual’s right to receive services in the most integrated setting combined with the

burdensome administrative challenges in trying to impose cost sharing on long term services and supports argue against putting cost sharing in place for recipients of LTSS. If CMS chooses to retain the State option to impose cost-sharing on Medicaid HCBS recipients, the regulations should make clear that States contemplating imposing cost sharing on individuals who receive Medicaid LTSS should be mindful of their obligations under the Americans with Disabilities Act and the Olmstead decision. See *Fisher v. Oklahoma Health Care Auth.*, 335 F.3d 1175 (10th Cir. 2003). Medicare has recognized this problem by removing Part D copays for individuals receiving home and community based services. See ACA § 3309 (eff. Jan. 1, 2012) (providing that dually eligible individuals who receive Medicaid home and community based services (HCBS), will no longer have a Medicare Part D copayment for their prescription medications). Medicaid should do the same.

Furthermore, states should have the express option to exclude medically frail individuals from cost sharing.

RECOMMENDATION: Amend § 447.56(a)(1)(v) as follows:

(v) Any individual who, as a condition of receiving services in an institution is required to spend all but a minimal amount of the individual's income required for personal needs. At state option, this exemption may be applied to or receiving services in a home and community-based setting if they are required to contribute to the cost of their care or through a Medicaid home and community based services plan of care. If application of cost sharing increases the risk that individuals will be subject to institutional care, the exemption will also be applied individuals who are medically frail or otherwise individuals with special medical needs as described in § 438.50(d)(3) of this chapter, individuals with serious, complex, or chronic medical conditions, individuals with a physical, intellectual or developmental disability that significantly impairs their ability to perform 1 or more activities of daily living, and individuals with substance abuse disorders.

Finally, CCD cannot envision how cost-sharing for LTSS would even be designed. Even assuming that cost sharing for LTSS could be advantageous, which CCD believes to be untrue, there are logistical problems that would prevent it being implemented successfully. As discussed above, even "nominal" cost sharing, if it were imposed for each episode of service provision, would mount up to a significant expense for a Medicaid beneficiary with a disability or chronic condition(s). CMS has asked for comment on "the unit of service for which separate cost sharing could be charged" (78 Fed. Reg. at 4659), but we know of no non-arbitrary way to define such a unit. To be sure, the impact of cost sharing on beneficiaries could be ameliorated somewhat by disregarding some specified portion of the LTSS provided, but such a disregard would be an arbitrary cap on cost sharing with no relationship to the purpose of cost sharing. Such an arbitrary disregard would only highlight the basic disconnect in the effort: cost sharing is designed to limit utilization of services, but it generally is in the interests of a Medicaid program to encourage utilization of community-based LTSS. A partial disregard of LTSS in calculating cost sharing raises the question of why cost sharing is being applied to LTSS in the first place.

Cost Sharing for Outpatient Services (42 CFR 447.52(b)):

CCD opposes the change in the proposed regulation for revising the structure for maximum cost sharing for outpatient services. Although HHS says in the preamble that very few services cost state Medicaid agencies less than \$50, CCD is concerned that, while this might be true in general, some people with disabilities and chronic conditions might be significantly impacted because they access services that are

under \$50 frequently. For example, it is our understanding that a blood draw is reimbursed at less than \$50 in some states. People with some chronic conditions might need to have blood drawn once a week. If the current copay for that blood draw is \$1.90 and the new allowable maximum of \$4.00 is charged, the person would be paying \$8.40 more per month in co-pays. As stated above, research shows that even these nominal changes can prevent people from getting needed care. This increase in out-of-pocket costs might cause the person in this example to skip a blood test, resulting in potential negative health consequences and increased costs later to address the resulting decline in health or function.

Cost-Sharing for Prescription Drugs (42 CFR §447.53):

Increases in drug cost-sharing could limit access to needed therapies and may put beneficiaries' health at risk and increase overall costs

CCD is extremely concerned that the proposed increases in Medicaid copayments would lead to burdensome cost-sharing levels for many of the low-income beneficiaries impacted by the changes, which research suggests would result in lower levels of adherence and potentially costly health complications. Among those hardest hit by the proposed changes would be Medicaid beneficiaries with significant disabilities who take multiple drugs to control chronic conditions and thus could face substantial cumulative costs for their medicines. These vulnerable individuals could face high out-of-pocket costs that would essentially penalize them for trying to maintain their health. As discussed above, research has shown that increases in co-payments are associated with failure to adhere to prescribed treatment and poor health outcomes. Medicaid beneficiaries typically do not have substantial choice of plans with alternative formularies which might better meet their needs, and for beneficiaries in fee-for-service Medicaid these copay increases would come on top of the very strong tools that states already use to drive use of medicines to the drugs states prefer.

Medicaid beneficiaries living with disabilities fill an average of 33.6 prescriptions per year. The treatments associated with these conditions are often "maintenance" medicines that require refills at regular intervals, leaving Medicaid beneficiaries with chronic conditions to bear a potentially burdensome level of monthly out-of-pocket costs if copays are set at more than nominal amounts. Cost-sharing increases are a blunt instrument virtually guaranteed to have adverse effects on utilization and health. CCD believes that it would be far more productive to develop targeted initiatives designed to make better use of medicines by improving adherence and reducing errors.

While the five percent cap on total out-of-pocket health spending is an attempt to shield this population from high costs, CCD believes that it is insufficient. Several states now limit total monthly co-payments so that beneficiaries who need multiple medications to maintain their health or treat serious illnesses are not penalized or discriminated against. CCD suggests that such an additional cap be included in the final rule as a necessary protection for this vulnerable population. For example, Montana has a cap of \$25 per month and Wisconsin has a cap of \$12 per month.

Numerous studies such as those cited above in our comments have shown that increased co-pays are associated with lower medication adherence and poorer health outcomes across the entire population, and the impact of increasing cost sharing is particularly acute for low-income patients. While the cost-sharing levels being proposed in the rule may seem reasonable when compared to a commercial insurance plan, these co-pays will be a significant barrier for many very low-income beneficiaries. Higher copayments could limit patient choice and force changes in prescribed treatment, even when not medically appropriate.

In many drug classes, therapeutic substitution between a brand name drug and a chemically different generic drug is not medically appropriate. According to the Congressional Budget Office (CBO), even among drugs approved to treat the same condition, some drugs in a class may be more effective than others for different patients. The definition of preferred drugs included in the proposed rule does not include any protections that would ensure that a range of drugs will be available to provide access to the medications most appropriate for their care without high cost sharing. Given the complex health conditions of many Medicaid beneficiaries with significant disabilities, it is crucial that the program's cost sharing rules provide meaningful access to beneficiaries who may need innovative therapies that cannot be easily substituted to maintain their health.

The proposed cost-sharing changes for non-preferred drugs are particularly concerning because of the difficulties in substituting medications that treat conditions where the effectiveness of drugs is very individual in nature, including, but not limited to, serious mental illness, Multiple Sclerosis, and epilepsy. To use mental illness as an example, a recent study in Health Affairs reported that "drugs might not be equally effective for an individual patient. Prior studies have shown that failure to respond to one SSRI or having severe side effects does not mean that the patient will have the same experience with another SSRI."

The Congressional Budget Office recently recognized the offsetting effects of prescription drug utilization when it adjusted its methodology to account for savings in other health care services that accompany an increase in the use of prescription medicines in the Medicare population. Given the high prevalence of serious health conditions among Medicaid beneficiaries, the cost-sharing changes proposed for prescription drugs may both reduce adherence and increase the share of beneficiaries who need expensive medical and surgical interventions. These negative effects could counter any health savings achieved by the higher cost sharing itself.

In addition, CCD believes that the proposed cost-sharing amounts for non-preferred drugs for those with income under 150% of FPL exceed the nominal limitation in the statute and undercut the Medicaid program's goals. The proposed \$8 copayment for non-preferred drugs for beneficiaries with incomes below 150% of FPL exceeds the statute's "nominal" cost-sharing requirements. CCD urges CMS to reduce the proposed maximum cost-sharing levels for non-preferred drugs so that they satisfy statutory requirements (including cost-sharing limits in §§ 1916 and 1916A) and align with the purposes of the Medicaid statute. § 1916 generally limits cost-sharing for drugs to "nominal" amounts, which must be "determined by the Secretary in regulations which shall... take into account the level of cash assistance provided in such State and such other criteria as the Secretary determines to be appropriate." "Notwithstanding" § 1916, § 1916A allows States to adopt a State plan amendment with more flexible cost-sharing rules. But even under § 1916A, cost sharing for non-preferred drugs for individuals with family incomes at or below 150% of FPL or who are exempt from non-drug cost-sharing cannot exceed "the amount of nominal cost-sharing (as otherwise determined under § 1916)." Thus, CMS may not set "nominal" amounts for non-preferred drug purposes that exceed the "nominal" amounts it sets under § 1916; it must set a uniform amount that applies under both provisions. Here, CMS proposes to set the nominal cost-sharing amount for outpatient services under § 1916 at \$4. CMS identifies the proposed \$4 "nominal" amount under SSA § 1916 very explicitly, stating that:

Under the authority granted under sections 1916(a)(3) and (b)(3) of the [Social Security] Act for the Secretary to define nominal cost sharing, at § 447.52(b) we propose to revise the maximum amount of nominal cost-sharing for outpatient services Currently, maximum allowable cost sharing is tied to

what the agency pays for the service. This can be confusing and burdensome for States, providers, and beneficiaries. To simplify the rules, we propose to remove the State payment as the basis for the cost-sharing charge and replace it with a flat \$4 maximum allowable charge for outpatient services. The \$4 charge for outpatient services is comparable to the amount States may charge under current rules (\$3.90) for services on which the State pays more than \$50.

Under § 1916A, the maximum cost-sharing for non-preferred drugs for individuals with income at or below 150% of FPL (or who are exempt from non-drug cost sharing) cannot exceed a nominal amount “as otherwise determined under section 1916.” The proposed rule would set the § 1916 “nominal” amount at \$4, but would set the § 1916A non-preferred drug cost sharing for groups who can only be charged the “nominal” amount “determined under section 1916” at \$8. This would violate the law. Accordingly, CMS should reduce the proposed \$8 maximum cost-sharing amount for non-preferred drugs for individuals with income at or below 150% of FPL (or who are exempt from non-drug cost sharing) to \$4, to match the nominal cost sharing amount under § 1916.

Not only does the proposed cost sharing increase for non-preferred drugs for individuals below 150% of FPL violate the requirements of the § 1916, the increase is also unnecessary to achieve the policy goal of incentivizing the use of preferred drugs. Even with a \$4 maximum copayment for both preferred and non-preferred drugs, a state could create a strong incentive for the use of preferred drugs by lowering the copayment for those drugs to \$1 or eliminating copayments on those drugs. This would meet both the requirements of § 1916 and also provide states with the tools necessary to drive drug utilization towards preferred drugs.

CCD also believes that the proposed standard for determining which drugs are non-preferred is inappropriate and does not include the anti-discrimination protections contained in the ACA. The proposed rule defines preferred drugs with respect to a cost-effectiveness standard. Specifically, preferred drugs are those “the State has identified on a publicly available schedule as being determined by a pharmacy and therapeutics committee for clinical efficacy as the most cost effective drugs within each therapeutically equivalent or therapeutically similar class of drugs.” Use of a cost-effectiveness standard as the basis for identifying preferred drugs in State Medicaid programs threatens access to needed treatment and would result in broad, one-size-fits-all policies that do not reflect important differences in individual beneficiary needs and circumstances. A cost-effectiveness standard should not be defined in Medicaid in a way that compromises access to needed care. In the case of Medicaid, the statute requires going beyond cost effectiveness and also applying the non-discrimination standards in ACA to the newly eligible individuals who will be enrolled in Alternative Benefit Plans (ABPs). The ACA’s anti-discrimination standards apply to all plans required to provide Essential Health Benefits and were included in the law to prevent plans from designing benefits that would discriminate against patients with significant health needs.

The ABPs that will cover newly eligible beneficiaries must provide “at least essential health benefits as described in section 1302 of [ACA]” the EHB requirements include that CMS not make coverage or other benefit design decisions that discriminate against individuals because of age, disability, or expected length of life ; that EHBs take into account healthcare needs of diverse segments of the population, including women, children, disabled individuals, and other groups ; and that EHBs not be denied to individuals against their wishes due to expected length of life, present or predicted disability, degree of medical dependency, or quality of life. To help carry out these EHB mandates, CMS has proposed that “[e]ssential health benefits cannot be based on a benefit design or implementation of a benefit design that discriminates on the basis of an individual’s age, expected length of life, or of an individual’s

present or predicted disability, degree of medical dependency, or quality of life or other health conditions.” Similar to ACA § 1302 itself, the proposed rule would therefore prohibit ABPs from employing any benefit design that discriminates based on an individual’s age, expected length of life, or any of the individual’s health conditions.

This important beneficiary protection applies to any aspect of “benefit design.” Yet it is not reflected in the proposed rule’s provisions on cost-sharing: a central feature of benefit design that often determines whether beneficiaries have affordable access to “covered” treatments. To meet the nondiscrimination requirements that govern Medicaid ABPs, CMS should require that these plans classify drugs as “preferred” or “non-preferred” drugs in a way that “[does not] discriminate on the basis of an individual’s age, expected length of life, or... present or predicted disability, degree of medical dependency, or quality of life or other health conditions.”

Meaningful non-discrimination protections will require a thoughtful and thorough review of preferred drug lists (PDLs). For example, PDLs should only be permitted to categorize a drug as non-preferred when there are genuine therapeutic alternatives classified as preferred. In addition, PDLs should allow for appropriate access to drugs or drug classes needed for adherence to widely accepted treatment guidelines. Most importantly, medications used by particularly vulnerable Medicaid beneficiaries, such as those living with serious mental illness, should be largely available as preferred drugs, given the importance of avoiding medical complications and interruptions in therapy for individuals with those conditions.

Finally, § 1916A explicitly requires that Medicaid provide preferred cost sharing on non-preferred drugs “if the prescribing physician determines that the preferred drug for treatment of the same condition either would not be as effective for the individual or would have adverse effects for the individual.” This is an important patient protection, and a telling recognition that high cost sharing can be a complete barrier to access: the equivalent of not covering a drug at all.

CCD commends CMS for proposing regulatory language to implement this statutory requirement. A simple and prompt process for patients or their physicians to invoke this statutory protection and get the cost-sharing for a “non-preferred” drug reduced to the preferred level is essential. For example, patients who have already tried “preferred” drugs in a therapeutic class without good results should promptly receive access to a “non-preferred” drug on preferred cost sharing terms. CCD would therefore encourage CMS to add more specificity to the proposed regulatory language, so as to ensure that this process works smoothly and quickly to get Medicaid beneficiaries access to needed medicines.

Emergency Department Services (42 CFR §447.54):

CCD understands and supports discouraging the use of the emergency room for non-emergency services. CCD is very concerned though about the potential to charge enhanced co-pays for people who do not have access to adequate care providers outside of an emergency setting. As such, CCD supports the requirements proposed to be put in place to verify that care is available in a non-emergency setting before applying higher cost sharing but is concerned about enforcement of this provision. To that end, CCD encourages CMS to include in the final rule:

- Oversight, reporting and other requirements to ensure that the higher cost-sharing is not imposed without the verification of non-emergency care availability.

- Create enhanced requirements for verification in rural and other areas where there is a shortage of primary care physicians and specialists that will see Medicaid patients.

Coverage and Cost-Sharing for Prevention Services (Section 440.347 and Section 447.56)):

CCD strongly commends HHS for including in ABPs the full range of preventive services required in the EHB, including all of the PHSA § 2713 services. This is a critical provision for vulnerable populations and will help achieve the ACA objective of shifting health care emphasis from expensive interventions to cost-effective prevention. We urge HHS to explicitly state this requirement (currently in the preamble at 78 Fed. Reg. 4631) in the regulation itself. Please also see our comments to § 447.56(a)(2) below, recommending that HHS also apply the PHSA § 2713 cost-sharing protections to the § 2713 services in ABPs. This is essential to providing meaningful coverage to vulnerable populations and avoiding the unfair outcome of *greater* cost-sharing for *poorer* individuals.

Charging low-income individuals for services that higher income individuals will receive without cost-sharing in private plans is counter intuitive. Prevention services help keep individuals healthy and lower health care utilization as a result. Prevention services can prevent people with disabilities and chronic conditions from developing secondary conditions and very complex health needs. This is especially true because people with disabilities have higher rates of preventable secondary conditions and often get preventative care at a lower rate. For example, persons with disabilities are more likely to experience chronic health conditions than the general population. Persons with disabilities are more likely to be obese (37.6% vs 23.8%) and more likely to smoke tobacco (28.3% vs 16.1%).⁶ Women with disabilities, especially those with significant physical limitations, receive mammograms less often than women without disabilities. Women with disabilities may be at higher risk of late-stage breast cancer and higher mortality than women without disabilities.

Recommendation

Add to Section 440.347 a new provision

Preventive and wellness services under paragraph (a)(9) must include the services described in § 2713 of the Public Health Services Act.

Medicaid cost sharing protections related to preventive services must harmonize with the PHSA § 2713 cost sharing prohibitions. We urge HHS to amend Title XIX cost-sharing provisions to clarify that the preventive services included in the essential health benefits are exempt from cost sharing. Otherwise, low income individuals enrolled in Medicaid alternative benefit plans may be responsible for cost sharing for some of the preventive services that are available to higher income individuals in the private market with no cost sharing.

Recommendation

Amend Section 447.56(a)(2) by adding

(iv) Preventive services provided in accordance with § 440.347

⁶ CDC (2011) - CDC Health Disparities and Inequalities Report.

Premiums (42 CFR §447.55):

CCD commends HHS for including those who are provided medical assistance under 1902[a][10][A][ii][XV], [XVI] and Ticket to Work and Work Incentives Improvement Act [TTWWIIA] under exceptions to the premiums that can be charged individuals with income above 150% FPL. The proposed rule provides that these individuals *may be charged premiums on a sliding scale based on income* and ensures the preservation of premium arrangements that were created under these sections of the law to encourage work efforts by Social Security beneficiaries.

Limitations on premiums and cost sharing (42 CFR § 447.56):

CCD is deeply troubled by new limitations on the application of a 5% aggregate cap on cost-sharing for Medicaid beneficiaries. Whereas current rules at § 447.78(a) and (b) apply this cap broadly, the proposed rule selectively applies this cap. The omission of a 5% aggregate cap for Medicaid beneficiaries below 100% of FPL violates statutory requirements at 42 U.S.C. § 1396o-1(a)(2)(B). The May 2010 final rule that implemented the § 447.78 notes that §§ 1396o and 1396o-1 should not be read in isolation, for to do so “would frustrate the statutory purpose and permit a State to effectively impose aggregate cost sharing far in excess of 5 percent of family income by using the two statutory cost sharing options cumulatively.” (75 Fed. Reg. 30253). This is exactly what the proposed rule would do for any group not listed in § 447.56(f)(2). In HHS’ own words:

Such a result would be an inadequate beneficiary protection and would not achieve the statutory purpose of the aggregate limit. The clear statutory purpose is to limit family cost sharing obligations to 5 percent of family income and that purpose can be achieved only if the aggregate limit applies to all cost sharing imposed under the State plan for all family members, including cost sharing imposed under section 1916. (75 Fed. Reg. 30253)

Such changes significantly erode one of the most critical beneficiary protections and add administrative complexity because states will have to employ more complex tracking systems. HHS also pledges in the preamble that the proposed rules will “greatly simplify and streamline the cost sharing regulation ‘in a manner that is consistent with simplicity of administration and the best interests of the recipients,’ in accordance with section 1902(a)(19) of the Act.” (78 Fed. Reg. 4595.) The changes proposed here are most certainly not consistent with § 1902(a)(19), which was correctly invoked to explain the implementation of § 447.78. HHS has provided no rationale to explain this major regulatory change.

Even if HHS elects to continue with a selective application of the 5% aggregate cap, it is imperative for the regulations to apply the cap to all individuals below 100% of FPL. This omission clearly violates 42 U.S.C. § 1396o-1(a)(2)(B), which applies the cap to all individuals covered under § 1396o. We see no alternative interpretation, certainly not one in the best interests of the beneficiary, that would permit a State to apply cost sharing to the very poorest of the poor – individuals below 100% of FPL – without subjecting that cost-sharing to a 5% aggregate cap. As a matter of policy, that the copayment may not be mandatory for them to pay is irrelevant to the effect that unlimited copayments will actually have on these poor who are trying to pay the copay charge.

RECOMMENDATION: Delete proposed § 447.56(f)(1) & (2); redesignate paragraphs (3)-(6) as (2)-(5), respectively; and add new § 447.56(f)(1) as follows:

(f)(1) The total aggregate amount of premiums and cost sharing imposed under sections 1916 and 1916A of the Act for all individuals in a family enrolled in Medicaid may not exceed 5 percent of the family's income for the monthly or quarterly period, as specified by the state.

If HHS refuses to maintain the current universal cap, it should at the very least amend § 447.56(f)(2), by adding a new subsection (i) and re-designating the subsequent subsections as follows:

(i) Individuals whose family income does not exceed 100 percent of the poverty line applicable to a family of the size involved minus the MAGI disregard; . . .

III. Medicaid Eligibility Part 2

Delegation of Appeals Authority 42 CFR § 431.10(c):

CCD believes that HHS must require close supervision and oversight when notice and hearing functions are carried out by a government entity other than the single state agency. We support HHS' decision to provide that Medicaid agencies may only delegate responsibility to conduct fair hearings to a government agency or public authority that maintains merit personnel standards. Indeed, this is necessary to comply with the requirement in section 1413(d)(2)(B) of the ACA that eligibility determinations be made by public agencies. Given the troubled history of private contractors determining Medicaid and CHIP eligibility in some states (e.g. California, Indiana, Texas), there are serious concerns about the lack of transparency, accountability and accessibility when this authority is delegated away from public agencies. See, e.g., Manju Kulkarni et al., *Public Health and Private Profit: A Witch's Brew*, J. POVERTY LAW & POL. (Jan.-Feb. 2002). At any rate, as we have noted in previous comments and HHS has acknowledged, this is a long-standing feature of the Medicaid program.

Requirement for written agreements 42 CFR § 431.10(d):

We support HHS' requirement that the Medicaid agency and Exchange or Exchange appeals entity have written agreements that provide for the relationships and responsibility, quality control, and assurances and procedures to ensure that fair hearings comply with applicable requirements. We recommend that HHS require that the agreement explicitly provide for compliance with the monitoring and reporting requirements and the specific information be reported. We also believe that such agreements must be made available to the public.

RECOMMENDATION: Revise § 431.10(d) as follows:

(d) . . . The plan must provide for written agreements between the Medicaid agency and the Exchange . . . and must include provisions for:

. . .

(2) Quality control and oversight by the Medicaid agency, including any reporting requirements needed to facilitate such control and oversight, including any reporting requirements needed to facilitate such control and oversight but not limited to the following monitoring and reporting requirements: (i) Total number of appeals received by the Medicaid agency and the Exchange or Exchange appeals entity in the applicable period; (ii) Number and percent of Medicaid or Exchange appeals resolved through the hearing process and the outcomes of cases in the period; (iii) Quality improvement activities related to issues identified through the reports and monitoring. . . .

(5) Making such agreements publicly available upon request and by posting to a dedicated appeals section on a public website.

Definitions (42 CFR § 431.201):

CCD supports the expanded definition of an “action” and clarification that actions include determination of medical expenses to establish spend-down liability or of income for the purpose of determining cost sharing amounts. Such determinations have always been “actions,” however, this amended definition will bring welcome clarity to this area.

We note that this definition has been reworded in a way that suggests that termination or suspension of benefits or services is not an action. We assume that this is not HHS’ intent, because it would be inconsistent with Goldberg and its progeny. Accordingly, recommend amending the language.

RECOMMENDATION: Revise § 431.201’s definition of “Action” in the following manner:

Action means a termination, suspension, or reduction of Medicaid eligibility or a termination or suspension of, or reduction in the level of benefits and services . . .

Accessibility of hearing system (42 CFR §431.205):

CCD supports HHS for including the requirement that the hearing system be accessible to persons who have disabilities and who are limited English proficient. CCD believes this should be strengthened by including a specific statement regarding prohibition of discrimination in the hearing system. Such statement should detail that the hearing system must not discriminate against any individual on the basis of race, color, national origin, language, sex, sexual orientation, gender identity, age, or disability. Further, the regulation should specifically note that the hearing system must comply with Title VI, the Rehabilitation Act, § 1557 of the ACA and other applicable federal statutes and regulations. So that marketplaces have sufficient time to develop the systems and implement this system upon launch in October, we recommend that HHS issue sub-regulatory guidance quickly.

RECOMMENDATION: Amend § 431.205 to add new subparagraph (f) as follows:

(f) The hearing system must not discriminate against any individual on the basis of race, color, national origin, language, sex, sexual orientation, gender identity, age or disability. The hearing system must comply with Title VI of the Civil Rights Act of 1964, the Rehabilitation Act, the Americans with Disabilities Act, and section 1557 of the Affordable Care Act.

Notices:

CCD strongly supports making notices as easy to understand and reducing the need for multiple notices to applicants and beneficiaries whenever possible. Although the single streamlined application process is designed to make things easier and understandable for people, CCD remains concerned that people will not understand their options and end up in the eligibility category they are entitled to and best meets their health care needs. CCD appreciates HHS’ efforts to ensure that notices are clear and accessible and the attempts to minimize the confusion of applicants and beneficiaries. CCD supports the requirements that notices must be written in plain language, be limited English proficiency accessible, and accessible to people with disabilities.

CCD strongly supports including language in notices regarding possible non-MAGI eligibility to both people found eligible for the Medicaid expansion group and those who are found ineligible for Medicaid through any MAGI eligibility category. CCD encourages HHS to include this notice requirement to people found ineligible for Medicaid because their MAGI was too high as well because their income might not be too high to qualify under a disability category.

People who might be eligible on the basis of disability or the need for long-term services and supports must be informed of the potential availability of access to Medicaid on these other bases. CCD believes however that the language in 42 CFR §435.917 (c) should be strengthened to ensure applicants understand their options. HHS should in the final rule require:

- All potential additional bases for eligibility be listed
- A complete description of the services and supports available through the other bases
- Where to go for assistance in determining whether this might be applicable to the individual

CCD also encourages HHS to require the inclusion of information in notices about the responsibility of individuals to report changes in health status or service needs to the Medicaid agency. CCD is concerned that a healthy individual who enrolls in the expansion group but develops a new condition or has an existing condition that worsens will not know there is the possibility of getting additional services to meet their needs. Requiring states to include language in all Medicaid approval notices that informs beneficiaries that they might be entitled to a different service package at any time (not just at redetermination) if their health worsens or their service needs change could help ensure that people are aware of the potential availability of other services as well as the fact that it is their responsibility to make the Medicaid agency aware of such changes.

Informing applicants and beneficiaries (42 CFR §431.206):

As mentioned above, CCD strongly support the inclusion of specific language requiring that the information required in this section must be accessible to LEP individuals and individuals with disabilities. This comports with the due process requirements of the U.S. Constitution as well as Title VI, the Rehabilitation Act, and section 1557 of the ACA.

Agencies have a proactive obligation to inform applicants and the public that they have a right to reasonable accommodations and policy modifications, such as alternative formats or assistance with filling forms. If the agency or its representatives have information that the individual is LEP or has a disability requiring use of an augmentative or assistive communication device, the agency should be required provide notices to the individual in that language or in an alternative format. If the agency fails to do this, the notice would automatically be deemed ineffective because the notice is insufficient given the individual's language or disability.

Further, since some agencies may not have comprehensive language data on all individuals, we recommend that HHS require taglines in at least 15 languages on all notices. These taglines are an effective and cost-efficient way to inform LEP individuals that the notice is important and how to obtain further information through written translation or oral communication services. As mentioned above, sub-regulatory guidance from HHS would be most helpful.

RECOMMENDATION: Amend § 431.206 as follows:

(e) The information required under this section must be accessible to individuals who are limited English proficient and individuals with disabilities, consistent with § 435.905(b) of this chapter and may be provided in electronic format in accordance with § 435.918 of this chapter. The information must also include the following:

- (1) for any individual with a disability, information must be provided in an alternative format appropriate for the individual's disability , with primary consideration given to the requests of the individual with disabilities;
- (2) for any individual with a visual impairment who is unable to read standard information, the agency must provide information in large print, Braille or other acceptable alternate format appropriate for the individual's disability;
- (3) for any individual the agency knows or should reasonably know is LEP, information must be provided in that individual's language; and
- (4) for all notices, the agency must provide taglines in at least 15 languages informing individuals of the availability of written translations or oral assistance and alternative formats to understand the information provided and a toll-free telephone number to request assistance.

Content of Notice (42 CFR § 431.210):

CCD supports the language indicating that a "clear" statement of "the specific reasons" for an action must be included in notices. Moreover, we commend HHS for clarifying that citing the regulation supporting an action does not satisfy the requirement for a clear statement. 78 Fed. Reg. at 4602. As HHS notes, it is crucial that notices inform individuals of the facts supporting the denial of eligibility, not just the law. This is particularly true because multiple paths to insurance coverage exist, a variety of rules govern them, and more and different types of entities are making determinations. Thus, the likelihood of applicants and beneficiaries having difficulty understanding why they have been denied coverage is significantly greater than it has ever been and clarity and detail more important than ever.

As explained below, in the discussion of the procedural rights of applicants and beneficiaries, we believe that individuals who are entitled to hearings on both Exchange and Medicaid eligibility determinations should have the option of requesting that the hearing on Medicaid eligibility be conducted first. Accordingly, we recommend that the required content of the notice include this information.

RECOMMENDATION: We recommend adding the following language to § 431.210(d)(1):

. . .or State agency hearing, and to request that such hearings take place before any hearing on an Exchange determination.

Certified Application Counselors (42 CFR §155.225):

CCD appreciates that HHS reiterated the standards and requiring training for authorizing application counselors to assist people to complete their applications for initial eligibility and renewal. CCD appreciates that CMS recognizes the importance of community based organizations providing application assistance to potentially eligible individuals. Many disability organizations assist individuals to apply for Medicaid and other programs. CCD also supports efforts to ensure that training is provided to community groups to ensure that the counselors are knowledgeable about the insurance affordability provisions, Medicaid, and how to ensure confidentiality. CCD also supports the prohibition on charging for application assistance. However, CMS should clarify in the final regulations how the training will be provided. States need to ensure that any potential costs involved in the certification process are not prohibitive and do not prevent organizations from providing these critical services. Making the training available online and at no cost would go a long way toward helping ensure that community organizations currently providing assistance can continue to do so.

Throughout the rule, the HHS requires that information provided to applicants and enrollees be easy to understand and be of sufficient detail to support informed decision-making by individuals in selecting health plans. Because counselors may be called on to provide information and referral services, CCD believes it is essential that the counselors are providing training on where to direct people with disabilities who seek assistance with employment. Many states already operate online benefits counseling programs that could serve as resources for this purpose. CCD urges HHS to include information regarding these benefits counseling programs and other resources regarding employment for people with disabilities part of required training for application counselors.

CCD agrees with HHS that there are considerable complexities involved in correctly screening people under the various eligibility categories and application of varying levels of cost sharing under the ACA. It is important that working people with disabilities understand fully their options for obtaining health care coverage either through extended Medicare, Medicaid or an exchange. People with disabilities who qualify for the expansion group may also be eligible under another eligibility category and want to be screened for another eligibility group if it would better address their needs. Any confusion or seeds of doubt sown by conflicting or misleading information may discourage many individuals with disabilities from attempting work or maintaining employment.

We appreciate that HHS has reiterated the responsibility of Exchanges to certify application assisters to ensure that their programs provide equal access to individuals with limited English proficiency and individuals with disabilities. Our experience with Medicaid and CHIP programs, however, is that these longstanding obligations for equal access are often poorly implemented. We strongly urge HHS to provide Exchanges specific guidance and examples of how they can effectively meet the needs of individuals with disabilities and LEP individuals.

Further, we recommend that the certification process for application counselors (as well as navigators) include specific training components that provide information on how to provide culturally and linguistically appropriate services. These components should address not only LEP and people with disabilities but also how to assist other underserved communities such as LGBT individuals, immigrants, and people of color. Such training is critical to ensure that the marketplaces, Medicaid and CHIP agencies are indeed welcoming to all individuals and can appropriately assist with their needs. The assistance must be applicant/enrollee-centered and thus application counselors must respond to the

varying cultural, linguistic and other needs of applicants rather than expect applicants to fit into predetermined roles.

Training should also include components on how to access and work with interpreters (if competent bilingual staff is unavailable) and how to access and use augmentative and assistive communication devices to assist individuals with disabilities. This information should provide the foundation for providing high quality, culturally competent and applicant-centered assistance but will require ongoing monitoring to ensure effective utilization.

Further, application counselors should have access to population-level data. Application counselors must use available population-level data to help determine the needs of the population(s) served. These data sources may include for example, census figures, voter registration data, and school enrollment profiles. The needs of the population(s) served may be based on the following demographic characteristics:

- Age
- Sex
- Disability
- Language(s)
- Race/ethnicity
- Religion(s)
- Socioeconomic status
- Education level
- Sexual orientation
- Gender identity or expression

We strongly recommend that the discussion in the preamble about requirements to comply with equal access also appear in the regulatory text.

To ensure that all eligible persons are enrolled, and that counselors comply with civil rights and privacy laws and reduce administrative errors and costs, counselors should receive effective training to avoid creating obstacles to participation and about what questions are –and more importantly are not required – of certain immigrants and/or non-applicants.

RECOMMENDATION: Amend § 155.225 to add new (b)(9):

(9) Effectively trained in providing enrollee-centered services in a culturally and linguistically appropriate manner. The training must include, at a minimum: the requirements of Title VI of the Civil Rights Act of 1964, the Rehabilitation Act, the Americans with Disabilities Act, and section 1557 of the Affordable Care Act; how to access and provide language services; how to access and utilize augmentative and assistive communication devices; how to provide culturally competent services; eligibility requirements for immigrants; and what information is not required for non-applicants.

Finally, CCD reiterates its recommendations we submitted in our comments in response to the proposed regulations for the Navigator program in the exchange. Ensuring Navigators are able to provide counsel to individuals with disabilities regarding their eligibility and enrollment is vital.

As we stated in those comments, 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.

Included in our recommendations were:

- Augmenting the tools and activities with a needs assessment and with measurable, auditable standards regarding the performance of the customer service activities and
- 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.

CCD also reiterates the importance of ensuring that Navigators are able to provide accurate information to people with disabilities regarding their plan choices and reiterates the recommendation to require 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.

Further CCD continues to recommend that the rules specify that Navigators be required to have 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.

Authorized Representatives (42 CFR §435.923):

CCD supports the addition of this definition. Authorized representatives are an important part of ensuring that people with disabilities, particularly those with intellectual and developmental disabilities,

have access to health insurance. It is critically important that the individual be able to select a trusted friend, family member or other person they choose rather than having to rely on legal guardians or other legal arrangements.

Premium Assistance (42 CFR §435.1015):

CCD supports extending the ability for States to use current premium assistance authority to purchase insurance through a QHP offered through the exchange. CCD urges HHS to consider putting in place additional protections to ensure people understand their rights and responsibilities and that their rights are protected. These protections should include specific requirements to:

- Ensure people understand they have access to all Medicaid benefits not covered by the QHP and how to access Medicaid benefits are that not covered by private insurance
- Ensure people to understand rules and cost-sharing between two different programs.
- Provide guidance on how to monitor that cost-sharing so that people do not exceed permissible cost-sharing.
- Create requirement for coordination between Medicaid and the QHP issuer to ensure the above occurs

CCD appreciates the opportunity to provide comments on the NPRM. If you have questions please contact Lisa Ekman, lekman@hdadvocates.org.

Sincerely,

The CCD Health Task Force Co-Chairs

Mary Andrus, Easter Seals, Lisa Ekman, Health and Disability Advocates, Theresa Morgan, ACCSES, Peter Thomas, Brain Injury Association of America, Julie Ward, The Arc

The CCD Long Term Services and Supports Task Force

Dan Berland, National Association of State Developmental Disabilities Directors, Maureen Fitzgerald, The Arc, Lee Page, Paralyzed Veterans of America, Laura Weidner, National Multiple Sclerosis Society,