United Spinal Association

Expanding Opportunities for Veterans
and All Paralyzed Americans

February 28, 2013

Attention: CMS Desk Officer
Office of Information and Regulatory Affairs
Office of Management and Budget

RE: Single Streamlined Applications: CMS-10438, CMS-10439 and CMS-10440

To Whom It May Concern:

United Spinal Association is submitting comments on the model streamlined application for the health insurance marketplace, Medicaid and CHIP. United Spinal Association shares the Centers for Medicare and Medicaid Services' (CMS) goal of expanding health insurance coverage to all Americans and making the enrollment process as streamlined as possible. In addition, the application process should help direct individuals to the health insurance program that will best meet their needs. The application form must include questions that can help screen when an applicant is a person with a significant disability or may need long term services and supports and would be eligible for traditional Medicaid. United Spinal does not believe that the two questions about disability in the proposed forms can accomplish these critical goals and recommends that they be replaced in the final model form.

CMS must also make the single, streamlined application and the application process for insurance affordability programs accessible to and usable by all users. The single, streamlined application must be available in alternative formats and accessible to people with disabilities, including those who are blind or have low vision. Further, on behalf of persons with intellectual, cognitive, and learning disabilities, we request that information produced for insurance enrollment and the new marketplaces should be written at an accessible reading level, preferably at the third grade level. The questions that collect disability data on the single, streamlined application should be standard questions. Videos must be closed-captioned. Navigators, responsible for providing assistance with the application process must be trained in how to address the needs of people with disabilities. Decisions about people with disabilities throughout this process should be made with input from focus groups made up of people with disabilities.

United Spinal Association is a national non-profit organization founded by paralyzed veterans in 1946 and has since provided service programs and advocacy to improve the quality of life of those across the life span living with spinal cord injuries and disorders (SCI/D) such as multiple sclerosis, amyotrophic lateral sclerosis, post-polio syndrome and spina bifida. There are more than a million individuals throughout the country with SCI/D and to whom the Association's work is dedicated. United Spinal has nearly 40,000 members, 30 chapters and close to 200 support groups nationwide. Throughout its history, United Spinal Association has devoted its energies, talents and programs to improving the quality of life for these Americans and for advancing their independence.

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United Spinal believes the purpose of the two disability questions is to identify individuals who may meet disability-based eligibility criteria and be eligible for "traditional" Medicaid rather than expansion-based Medicaid. Yet we also believe collecting this information is important to identify individuals who are medically frail and, if eligible for Medicaid, would be exempt from enrolling in an Alternate Benefit Plan (ABP). Providing the context for these questions is important so that individuals understand that identifying as having a disability may result in receiving more tailored services at less cost.

We believe the current questions on whether an individual has a disability and whether the applicant requires assistance with activities of daily living (ADLs) will not identify whether an applicant may be eligible for Medicaid on a basis other than MAGI or medically frail. Since the benchmark benefits available to newly eligible adults will likely be less robust than those in traditional Medicaid, it is very important that applicants have a full opportunity to determine eligibility for the health insurance program that best suits their needs.

Moreover, some individuals who have chronic or serious medical conditions that would likely qualify them for Supplemental Security Income (SSI) or state disability criteria and thus be eligible for Medicaid on the basis of disability may not self-identify as "having a disability." Therefore, the questions should be appropriately tailored to identify those individuals.

We do not think that the general population is trained or adept at understanding when they may have a disability or impairment that may qualify them for Medicaid or an exemption from ABPs and should not be called upon to make this determination unaided. Furthermore, research has consistently shown that asking people if they have a disability does not accurately identify people with disabilities. As such, we think it is best to ask a broadly inclusive question first, and allow trained state employees to make a later determination on whether someone does or does not have a disability for the purpose of state benefits. The point in the application is simply to flag those individual or family applicants who may qualify and therefore should be directed toward a state benefit determination first before obtaining private insurance through the Exchange. It should also flag individuals who may be medically frail, even if additional information is later needed to qualify for an exemption to ABP.

Thus we suggest that the application should focus on functional limitations rather than asking an individual to indicate that they have a "disability." People will often resist the label of "disability," but recognize that they have reduced functional capacity. For example, someone who is aging may readily acknowledge that they are having trouble hearing or seeing, but will not check that they "have a disability." People may also be fearful that answering yes to the question will have a negative consequence such as higher prices or being turned down for the insurance.

Disability is not simply the impact of impairment on, or its implications for, the individual, but also results from the interaction between an individual's impairment and the social, economic, and built environment. This current understanding of disability recognizes the impact of prejudice, discrimination, inaccessible architectural surroundings, and lack of accommodations such as Sign Language interpreters and accessible medical examination and diagnostic equipment. It replaces the long-held belief that disability equates inevitably with biologic dysfunction, disease and poor health.

In its International Classification of Functioning, Disability and Health (ICF), the World Health Organization (WHO) recognizes that factors outside the individual contribute to the experience of disability. The ICF calls disability an "umbrella term for impairments, activity limitations or participation restrictions," conceiving "a person's functioning and disability... as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors" including environmental

and personal attributes. The ICF aims to shift the disability paradigm to universality, encompassing everyone:

> Heretofore, disability has been construed as an all or none phenomenon: a distinct category to which an individual either belonged or not. The ICF, on the other hand, presents disability as a continuum, relevant to the lives of all people to different degrees and at different times in their lives. Disability is not something that happens only to a minority of humanity, it is a common (indeed natural) feature of the human condition…[1]

The ACA acknowledges both the prevalence of health disparities among people with disabilities and that health disparities are not the inevitable outcome of disability or disease, but are the result of complex factors including lack of disability awareness on the part of health care providers, and architectural and programmatic barriers to care. Thus, the ACA, in section 4302, calls for identifying disability status through population surveys and among applicants, recipients, or participants in federally conducted or supported health care or public health programs.

The single streamlined application should incorporate appropriate screening for persons with disabilities consistent with the ACA and advances made in the development of survey questions to identify persons with disabilities. The screening is essential to ensure that individuals have access to the right care for their needs.

For many years, the federal health-focused surveys have included questions that allow the identification of disability using a set of questions based either on activity limitation or functional limitation.[2] This provides a base upon which to identify individuals with disabilities through survey questions, which can be incorporated into the single streamlined application.

With regard to the second disability question proposed in the model application we find that equally problematic. People are not going to understand what the phrase "activities of daily living" is meant to describe. Furthermore, the question mixes the functional limitations of a person with services and supports to address the needs in a way that is both limiting and confusing. It is unclear why only personal assistance services or a medical facility are listed (nursing home is included in the online form). Individuals may misinterpret this to be asking if people want to go to a nursing home and skip this question. The relevance of "medical facility" is unclear" and people may not understand what is meant by personal assistance services.

Therefore, we recommend that the application include, the six questions used by ACS and several other federal surveys asking about functional limitations to help identify persons with disabilities. The questions should be accompanied by an explanation informing applicants that they may be entitled to a greater array of benefits if found eligible for traditional Medicaid. These additional questions may also help distinguish medically frail individuals who are also exempt from benchmark coverage.

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[1] T. B. Ustun, N. K. Kostansjek, and J. Bickenback. "WHO's ICF and Functional Status Information in Health Records." Health Care Financing Review 24, no. 3 (2003): 82.

[2] A number of national population surveys conducted or supported by the federal government collect data on disability status and on health services use and expenditures. The American Community Survey (ACS) and Current Population Survey (CPS) specifically ask questions that identify who have a disability. All the surveys with an explicit health information focus on the patient as the unit of analysis and, with only one exception, ask six or more questions about functional or activity limitation to identify respondents with disabilities.

RECOMMENDATION : Replace the two disability related questions with the following questions.

You may be eligible for another program that will better meet your needs if you answer yes to any of the questions below.

> ***Do you have a physical, mental, or emotional, health condition that causes limitations in any everyday activities? ☐Yes ☐ No (if Yes, please skip the following six questions)***
>
> 1) ***Are you/is this person deaf or have serious difficulty hearing?***
> 2) ***Are you/is this person or have serious difficulty seeing even when wearing glasses?***
> 3) ***Because of a physical, mental, or emotional condition, do you/does this person have serious difficulty concentrating, remembering, or making decisions?***
> 4) ***Do you/does this person have serious difficulty walking or climbing stairs?***
> 5) ***Do you/does this person have difficulty dressing or bathing?***
> 6) ***Because of a physical, mental, or emotional condition, do you/does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?***

Authorized Representative

United Spinal appreciates the inclusion of a brief explanation of authorized representative in the application forms. However we urge you to modify the language to reflect that the authorized representative can be a family member, a service provider, a much broader category of people than "trusted friend" or "partner." We recommend that the language be revised to read:

"You can give a trusted **person, including a family member,** permission to talk about this application with us, see your information and act for you on matters related to this application."

Accessible Application

The application provides the initial entry point to apply for health insurance and is a vital component of the Affordable Care Act's (ACA) "no wrong door" approach to enrollment. Yet, people with disabilities may suffer erroneous denials of eligibility because they cannot see and therefore read the application, or because they do not understand what information to provide. Indeed, they may be prevented or dissuaded from accessing the insurance marketplace altogether, undermining the goal of the ACA to expand affordable insurance coverage for all Americans.

The federally facilitated exchange (FFE) must comply with Title VI of the Civil Rights Act, Sections 501 and 508 of the Rehabilitation Act, and Section 1557 of the ACA. To prevent discrimination against people with disabilities, the FFE must ensure access and understanding for those consumers. In addition to the legal requirements, a fully accessible application would benefit all entities engaged in enrollment, outreach, and education. Accessible applications will assist in ensuring effective communication by creating a baseline for standardizing ACA-related enrollment terminology in an accessible format that can be used by other entities for outreach, education, and training. Accessible applications can also help train navigators in the new Marketplaces, who will assist people with disabilities, thus aiding effective enrollment and information dissemination.

Making applications accessible at the federal level is cost-effective for CMS and the states. For example, if the nineteen states operating state-based exchanges use the single, streamlined application but make their own accessibility accommodations, the costs multiply nineteen times. A federal investment results in significant efficiencies and economies of scale, benefitting virtually all Medicare and Medicaid providers who must comply with the Rehabilitation Act and Section 1557 of ACA.

Other Accessibility Issues

The online application must comply with Section 508 of the Rehabilitation Act and Section 1557 of ACA and be fully accessible according to Section 508 standards. The videos that CMS posted to Facebook to help explain the interactive online application process as part of the request for these comments were not close-captioned and were not in compliance with anti-discrimination laws. All videos distributed by CMS should be close-captioned to comply with Section 1557 of ACA, and Sections 508 of the Rehabilitation Act.

As someone suggested during one of CMS' webinars on the proposed application process, it would be helpful to have a button on the screen that says "read me" to provide access for people with disabilities, so they can acquire information via auditory input, or a combination of visual and oral input.

Disability Data Collection

The SHOP Paper Application contains no disability data collection questions, though racial and ethnic questions are included. If racial and ethnic data is collected, disability data should also be collected pursuant to the data collection provisions in Section 4302 of ACA.

The FA Paper Application poses the question "Have a disability __ yes ___no." It provides an alternative question to this question as follows: "Needs help with activities of daily living through personal assistance services or a medical facility __ yes ___no." This alternative question seems to create a new definition of disability not found in any other federal disability policy. This alternative question also assumes that everyone is familiar with the phrases "activities of daily living," and "personal assistance services," which are really terms of art. Further, this wording confuses readers as to whether or not it includes assistance of a family member or an unpaid persons who providers assistance.

We urge CMS to use the questions currently in use in the American Community Survey (ACS). These questions have been vetted, tested, and approved for data collection purposes in all federally funded health care, public health, and population data collection surveys and the single streamlined insurance Marketplace applications are being used to collect health data.[3] Should CMS chose to use questions other than the ACS questions, those substitute questions should be vetted and tested in the same manner as other questions approved for health data collections purposes under the standards set for Section 4302 of ACA.

Navigator Training

While CMS might say that navigators and the telephone assistance centers can provide access to the Marketplaces' application process for people with disabilities, we have serious concerns about that assumption. First and foremost, people with disabilities want to be able to do things independently-like everyone else. If the application and application process are made accessible according to Section 1557 of ACA and the Rehabilitation Act, people with disabilities should experience equal access. Should individuals with disabilities require assistance, navigators should be trained to meet the needs of people with disabilities so that they can be of assistance in a culturally competent manner. Further, telephone assistants also should be trained to meet the needs of people with disabilities in a culturally competent manner, including how to use the relay service to communicate with people with hearing impairments.

[3] See CMS document "Supporting Statement for Data Collection to Support Eligibility Determinations for Insurance Affordability Programs and Enrollment through Affordable Insurance Exchanges, Medicaid and Children's Health Insurance Program Agencies"

Inclusion of People with Disabilities in the Process

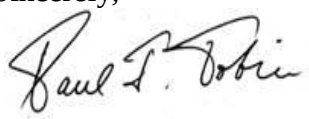
In the document accompanying the request for comments,[4] CMS states "We intend to undertake further consultation, conduct additional consumer focus groups, and engage experts in simplifying language and promoting a positive user experience based on the responses to this 30 day notice and continued stakeholder engagement." CMS must remember that people with disabilities are stakeholders. We urge CMS to include focus groups of people from the cross disability community to assure CMS has consumer input from representatives of *all* Americans. Our organization will gladly help CMS find participants with disabilities for its focus groups upon request.

Conclusion

We thank CMS for the opportunity to provide input to the single streamlined insurance Marketplace application process. We urge CMS to commit to work with the cross disability community and make the Marketplace application and the application process accessible and usable by people with disabilities. We urge CMS to adopt our recommendations to comply with the Rehabilitation Act and Sections 4302 and 1557 of the Affordable Care Act. Our organization stands ready to help CMS to implement these recommendations.

For more information, please contact Alexandra Bennewith, Vice President, Government Relations, United Spinal Association at (202) 556-2076, ext. 7102.

Sincerely,



Paul J. Tobin
President and CEO
United Spinal Association

[4] See CMS document "Supporting Statement for Data Collection to Support Eligibility Determinations for Insurance Affordability Programs and Enrollment through Affordable Insurance Exchanges, Medicaid and Children's Health Insurance Program Agencies,"