Disability Rights

Education & Defense Fund **DREDF**

December 28, 2012 **Via Email to Katie.Marcellus@hbex.ca.gov**

Ms Katie Marcellus
California Health Benefit Exchange Board
2535 Capitol Oaks Drive, Suite 120
Sacramento, CA 95833

Re: Addressing Health Equity and Health Disparities

Dear Ms. Marcellus:

On behalf of my organization, Disability Rights Education and Defense Fund (DREDF), I attended via phone the recent December 18, 2012 Covered California Board Meeting. While I have been unable to attend every 2012 board meeting, I have made comments over the phone or in person at a number of the meetings, and also submitted written comments on occasion. The dense December 18 agenda addressed a number of topics that are of concern to DREDF, including Health Equity and Health Disparities. During and after the meeting, I reviewed the Background Brief prepared by the Exchange staff, as well as the slide presentation. I do not believe we've met in person yet, but I shared some of my concerns about the Health Disparities Brief and planned presentation with Cary Sanders at CPEHN, and she gave me your email as a contact point.

I do first want to express whole-hearted support for Covered California's (Covered CA) decision to include the intertwined goals of promoting health equity and reducing health disparities in its organizational mission and values. DREDF is encouraged by the priority that Covered CA places on this topic, and the Exchange's acknowledgement of the potentially critical role it can play in achieving health equality and healthcare access for all Californians and the Exchange's consumers. However, I could not help but note that disability receives mention in only 2 places: inclusion among a list of other population characteristics in the definition of health disparity drawn from the National Partnership for Action to End Health Disparities, provided at the beginning of the brief, and Dr. Lisa Iezzoni's 2011 article on Eliminating Health and Health Disparities among the Growing Population of People with Disabilities, which is mentioned among the brief's reference materials.

I would like to draw the Exchange's attention to a growing body of research documenting the type and prevalence of health disparities among people with disabilities (PWD). Such mainstream and disability-specific entities as the U.S. Surgeon General, the Institute of Medicine (IOM), the National Council on Disability (NCD), the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ), the National Institute for Disability Rehabilitation

Research (NIDRR), and agencies of the National Institutes of Health have published seminal reports documenting unequal access to health care and health disparities experienced by PWD. The U.S. Department of Health and Human Services (HHS), in its Healthy People 2010 initiative, specifically called out the need to promote the health of PWD, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the American population, also recognizing that these goals would be increasingly important to an aging American population that will have an increased propensity to acquire functional impairments and disabilities.

The above confirms that the presence of physical, mental or cognitive impairments cannot be simplistically equated with the status of ill health. Rather disability is a population characteristic that is linked to numerous unnecessary, external barriers to health and healthcare such as physical and equipment barriers, ineffective communication, fewer preventive tests and counseling, insufficient provider expertise and coordination for individuals in a state of transition (e.g., moving from childhood to young adulthood) or with a dual diagnosis (e.g., a physical impairment and a chronic condition or a mental impairment), and, of course, lack of affordable or sufficient health insurance coverage. Covered CA could play an important role in redressing many of these deeply embedded systemic issues, but only if disability is equally included among the other disparity characteristics acknowledged by the Exchange.

DREDF has often encountered the assumption that PWD receive their care exclusively through public programs such as Medicaid, or Medicare as seniors. This is a false stereotype. It is true that disability status is associated with lower rates of both higher education and employment, and PWD are therefore disproportionately likely to be living at lower income levels, but this does not automatically equate with Medicaid eligibility. We have estimated that in 2010, there were as many as 3.5 million adults with disabilities living in the community with household incomes between 100 and 133% of poverty. Many of these individuals with disabilities will be state Exchange consumers, whether their state elects to expand Medicaid eligibility in line with the Affordable Care Act or not, since they are living at the edges of Medicaid eligibility.

Moreover, people with various functional impairments and chronic conditions are in the workforce, struggling to maintain and get by on exorbitant private individual and small group health insurance policies. Families of children with disabilities obtain multiple policies in an attempt to cover the coverage gaps of each policy, and seniors with disabilities face similar gaps and out-of-pocket expenses when they seek supplemental coverage. One 2008 study of over 28,000 households conducted by the University of North Carolina at Chapel Hill found that “solidly middle-class” families with children with disabilities “are struggling to keep food on the table, a roof over their heads, and pay for needed health and dental care.” These reports and others show that Exchange consumers will include PWD and their families. The healthcare barriers and disparities faced by PWD merit the acknowledgement and action of Covered California.

To be very clear, we have absolutely no objection to the Exchange addressing known barriers and gathering data pertaining to health disparities experienced by individuals who are members of racial and ethnic minorities have a lower socio-economic status, have a minority sexual orientation, or who live in particular geographic

areas/neighborhoods. We just strongly contend that disability must be included in all disparity measures undertaken by Covered CA, from plan management and delivery system reform to eligibility/enrollment data and analysis to stakeholder accountability. This is the case not just because PWD equally deserve and will benefit from those measures, but also because disability interacts with other population characteristics in ways that must be further explored. The HHS Advisory Committee on Minority Health has recently studied these links in its July 2011 recommendation Report on Assuring Health Equity for Minority Persons with Disabilities, concluding that "[i]t is particularly important to raise awareness about the dual burden of inequities that minorities with disabilities face." DREDF has also examined and written a short brief, attached, on the need to research, understand, and systemically address the often subtle ways that racial/ethnic status interacts with the fact of disability.

Since the disparities topic could not be covered in the very full December 18 Exchange board discussion, DREDF is hopeful that Covered California will take measures to include fully include disability health and healthcare disparities in the January meeting when the board will address this important issue publicly. Please let me know if DREDF can be of any assistance at that time, or if you have any questions about the above.

Best,
Silvia

Yours Truly,

Silvia Yee