I would like to thank Covered California and the board on behalf of Disability Rights Education and Defense Fund (DREDF) for the opportunity to speak on the important topic of health and healthcare disparities.

In the five minutes allotted, I cannot actually go into the details of what health and healthcare disparities for people with disabilities is, but I can implore each of you to visit my organization’s website, http://www.dredf.org/healthcare-stories/ where my colleague Mary Lou Breslin has created a series of health videos that capture the health care experiences of people with a variety of disabilities across the country, in their own words. Many of the individuals interviewed are privately insured. They work as consultants, are self-employed, or work in small businesses. They are Exchange consumers, and they speak for themselves more effectively than I ever could. Please take 10 minutes, choose any one of the videos, and listen to their words.

In my time today, I would like to make 4 specific, and dryer, points.

First, people with various disabilities, including those with significant functional impairments that affect hearing, vision, mobility, speech, concentration, memory, and the capacity to independently perform tasks such as dressing, bathing, cooking, shopping, and performing common errands, are NOT all on public health programs such as Medi-Cal or Medicare.

• As individual working adults and family members, people with disabilities seek and rely on private insurance, and many have historically been unable to obtain that insurance.

• The federal CMS Office of Communication, in a presentation entitled “an overview of CMS Consumer Research related to Audience Segmentation for the emerging health insurance marketplace,” found that 8.2% of the uninsured nationally are disabled.¹

• The same report divided the uninsured population into 6 market segments, characterizing the largest, 23.2%, as “sick, active & worried.” These are mostly Gen X and Baby Boomers, likely to be in poor health, and many are also

caregivers. They actively seek information for health issues, but may need help interpreting it. 79% say cost is a major reason they are uninsured, and 72% say they would be interested in shopping for insurance in the new marketplace.

If I cross the numbers from the CMS research with findings from the California HealthCare Foundation’s Dec 2012 Report, *California’s Uninsured: Treading Water,* specifically the number of 7.1 million uninsured under 65, I get a figure of 582,000 uninsured with disabilities. If I use CMS’s 23.2% figure, I get 1,647,200 “sick, active and worried” folks. It’s very hard to get more information about people with disabilities who are uninsured or who are on private insurance. I honestly do not know of any tool/survey that collects that information directly. This, in my opinion, is a key opportunity for Covered California and leads to my first recommendation – that Covered California actively seek and gather information about the needs of consumers with disabilities, where those consumers seek care, and the effectiveness, accessibility, and quality of the care that they receive.

Second, the reality that people with disabilities comprise a significant portion of CC’s consumer base leads to the need for detailed and concrete plans and standards for ensuring that outreach includes people with disabilities, including those with communication impairments that impact hearing, vision, and comprehension. I know that my colleagues at the California Foundation of Independent Living Centers have met with the Exchange and their contractor to report on the inaccessibility of PDF documents on the Covered California website. Our hope is that increased awareness of the need for compliance with Sections 504 and 508 of the Rehabilitation Act and the Americans with Disabilities Act will lead to proactive, front end, fully accessible materials and outreach from Covered California, and Covered California’s commitment to ensuring that people with disabilities are able to maintain accessibility throughout the selection, purchase, and maintenance of insurance through the Exchange. (As just one example of the difficulties of effective communication, I have a client who has been embroiled for almost two years in the simple attempt to get notices and information from his private insurer in either 24 font bold print or an electronic Word document. This is someone who is actively represented. There are thousands of blind and visually impaired Exchange consumers who do not have such assistance or resources.)

Third, assuming that Covered California and Qualified Health Plan communications become completely accessible, people with disabilities will need to find health plans that will be both affordable and will provide them with the coverage that they require to meet their healthcare needs, without being required to spend enormous amounts out-of-pocket for benefits that are especially limited or nonexistent in their plan.

One example of the way in which Covered California appears to be maintaining an ongoing healthcare disparity is the decision to use California’s small group business plan as an Exchange Essential Health Benefits (EHB) benchmark, with the result that actual benefits coverage will fail to meet the needs of many people with mobility

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disabilities, those with respiratory diseases and related conditions, and people with diagnoses related to complications of the digestive system.

- Many small group business plans in the state impose high co-pays/deductibles on durable medical equipment (DME) combined with an annual cap in the neighborhood of $2000 or $3000. DME includes everything from breathing ventilators to hospital beds to wheelchairs.

- While numerous DME items cost less than $100, the cost of an electric wheelchair can easily be $10,000-15,000, and that does not include the additional custom seating and other services that are needed to discussing the kinds of complex rehabilitation equipment that substitutes for the musculoskeletal functions that an individual's body cannot perform because of various disabilities.

- The annual $2000 limitation now appears to be imbedded in the Exchange’s EHB benchmark, placing the costs of medically necessary rehabilitation and habilitation equipment squarely on the shoulders of those who have significant mobility impairments or chronic conditions that lead to mobility impairments.

- I would also like to point out that the California Health Benefits Review Program (CHBRP) in June 2010 found that mandating the inclusion of DME in individual and group health insurance markets without unique co-pays or caps would lead to an average premium increase across all markets of .39%. The impact would be felt in the privately funded market segments, and would range from a net increase of $0.11 per-member-per-month (PMPM) in large-group CDI-regulated policies to a net increase of $3.64 PMPM in the individual DMHC-regulated plans. The CHBRP study was authored in response to AB 754, a bill authored by Assembly Member Chesbro and sponsored by DREDF and Disability Rights California. The bill would have mandated the coverage of medically necessary DME at parity with other benefit Coverage. The CHBRP study is available online at: [http://chbrp.ucop.edu/index.php?action=read&bill_id=108&doc_type=3](http://chbrp.ucop.edu/index.php?action=read&bill_id=108&doc_type=3).

Fourth, assuming that a PWD can get and afford a plan that actually provides the coverage that she or he needs in the exchange, there is still the matter of being able to get providers that can provide effective health care services.

Continuing with our example of people who have mobility disabilities, effective healthcare necessarily involves being appropriately examined and weighed during a medical appointment. Data derived from reviews of over 2300 primary care provider facilities in 18 of California’s 58 Counties, serving about 2.5 million Medicaid enrollees and an unknown number of non-Medicaid enrollees, reveals the extent to which height-adjustable exam tables and accessible weight scales are absent from provider offices.
Previous published literature had found that height-adjustable exam tables were present in 17-44% of provider offices, but those were studies with small numbers of participants (40 in 1 study, 68 offices in another), using sites that had essentially self-selected. From the California surveys, we found that 8.4% of provider sites have a height-adjustable exam table, and 3.6% have an accessible weight scale.4 What happens when a member with a plan purchased through the Exchange needs accessible equipment, or needs longer appointment times because she or he assists a non-verbal adult child with developmental disabilities, or needs American Sign Language interpretation for their own or a child’s appointment? Are they entirely on their own when it comes to finding primary care doctors or specialists or clinics who can provide them with effective care? Whose problem is it? How many people with disabilities – of all races, ethnicities, ages, genders, and sexual orientation – must be subject to disability-related disparities before it becomes everyone’s problem?

I would like to end by saying that DREDF wholeheartedly embraces CC’s goals. I love the aspiration that is “baked in” to those goals. For PWD this must mean not just getting more uninsured PWD signed for a product. It must include (1) detailed attention paid to the kinds of communication accommodations required by law, (2) providing affordable access to the range of essential health benefits that are critical to their ability to function in the community and live as independently as possible, and (3) providing information and pathways to providers and staff who have sufficient expertise and training in providing the kinds of reasonable accommodations are policy modifications that are practically needed on the ground to give people with disabilities effective healthcare.

If these needs are not met, Exchange consumers with disabilities will continue to face unique barriers to effective healthcare. Their health will get worse, their care will get more expensive, it will be difficult to work and find employment, and when this happens, I am afraid the story will once again inevitably be “a small percentage of people with disabilities and chronic conditions have high public expenses” instead of “insufficient effort is made in the health care market place to ensure that people with disabilities can get effective health care.”

Thank you.

4 These results have been published in Physical Accessibility in Primary Health Care Settings: Results from California On-site Reviews, N.R. Mudrick, M.L Breslin, M. Liang, S. Yee, Disability & Health J. July 2012; 5(3):159-167. Additional related publications include: Access to Subspecialty Care for Patients With Mobility Impairment: A Survey, T. Lagu et al., Ann Intern Med. 19 March 2013;158(6):441-446 (Of 256 practices, 56 (22%) reported that they could not accommodate the patient, 9 (4%) reported that the building was inaccessible, 47 (18%) reported inability to transfer a patient from a wheelchair to an examination table, and 22 (9%) reported use of height-adjustable tables or a lift for transfer. Gynecology is the subspecialty with the highest rate of inaccessible practices (44%)); Accessible Medical Equipment for Patients with Disabilities in Primary Care Clinics: Why Is It Lacking?, J. Pharr, Disability & Health J. April 2013, 6(2): 124-132; Predicting Barriers to Primary Care for Patients with Disabilities: A Mixed Methods Study of Practice Administrators, J. Pharr and M. Chino, Disability & Health J. April 2013, 6(2):116–123.