

# Health Disparities for People with Disabilities



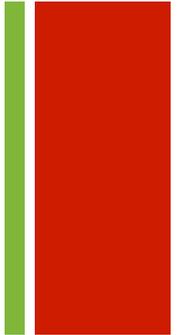
Disability Rights Education & Defense Fund

[www.dredf.org](http://www.dredf.org)

© Disability Rights Education and Defense Fund, permission to use with attribution



Disability Rights Education & Defense Fund



**Health Disparities Research  
At the Intersection of Race, Ethnicity, And  
Disability:  
a National Conference**

**April 25 & 26, 2013  
Washington, DC**

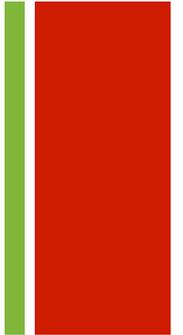
**Presented by Silvia Yee, Senior Attorney**

**[syee@dredf.org](mailto:syee@dredf.org)**



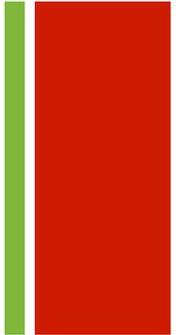
## Disability Rights Education & Defense Fund

- National law and policy center dedicated to protecting and advancing disability civil and human rights
- Vision: “A just world where all people live full and independent lives free of discrimination.”
- Our constituents are people with disabilities (PWD) of all ages and parents of children with disabilities
- Disability Rights are Civil Rights, and Health Care Rights *are* Disability Rights





# Disparities or Fact of Life?

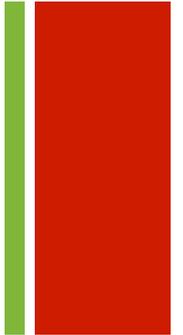


People with disabilities are more likely to:

- Experience difficulties or delays in getting the health care they need.
- Not have had an annual dental visit.
- Not have had a mammogram in the past 2 years.
- Not have had a Pap test within the past 3 years.
- Not engage in fitness activities.
- Use tobacco.
- Be overweight or obese.
- Have high blood pressure.
- Experience symptoms of psychological distress.
- Receive less social-emotional support.
- Have lower employment rates.

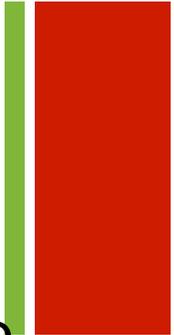


# Disability Discrimination & Disparities



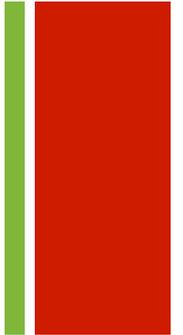
Disability is extremely diverse. While some health conditions associated with disability result in poor health and extensive health care needs, others do not. However all people with disabilities have the same general health care needs as everyone else, and therefore need access to mainstream health care services. Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD) reinforces the right of persons with disabilities to attain the highest standard of health care, without discrimination.

# Disability Perspective on Health



Health and wellness are not the same as the presence or absence of a disability; they are broader concepts that directly affect the quality of a person's life experience. Research and clinical experience have shown that persons with disabilities can be both healthy and well . . . . And good health opens the door to employment and education for persons with disabilities, just as it does for persons who do not have disabilities.

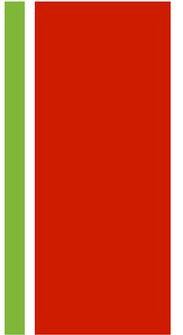
# + Defining “Disability”



Disability results from the interaction between an individual's functional impairments and his or physical, social, cultural, and economic environment

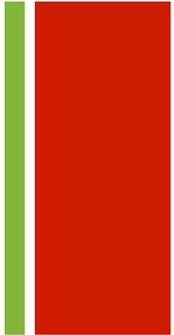
- Like many racial and ethnic minorities, people with disabilities are often socio-economically disadvantaged and subject to stereotypes and prejudices
- Unlike racial and ethnic minorities, the definition of disability is inherently linked to certain functional capacities that seem to challenge our understanding of the avoidable disparities experienced by people with disabilities

# Healthcare Barriers Leading to Disparities



- Physical and programmatic inaccessibility
- Prejudice and Stereotypes
- Lack of Provider Training and Cultural Competence
- Inadequate Research and Monitoring

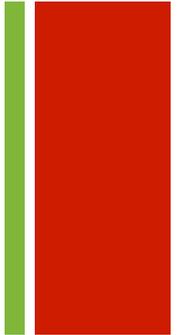
# Barriers: Physical & Programmatic



- 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, indicated 8.4% of provider sites had a height-adjustable exam table, and 3.6% had an accessible weight scale
- In a more recent and smaller-scale review of 256 specialty practices, 56 (22%) reported that they could not accommodate the patient, 9 (4%) reported that the building was inaccessible, 47 (18%) reported the inability to transfer a patient from a wheelchair to an examination table, and only 22 (9%) reported the use of height-adjustable tables or a lift for transfer. Gynecology is the subspecialty with the highest rate of inaccessible practices (44%)



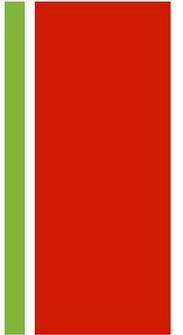
# Barriers: Prejudice and Stereotype



- When my son, who has cerebral palsy (CP), was around 2 years of age, I took him to visit an old college friend who had a child the same age. We hadn't been in touch for a while; she didn't know my son had CP. The visit was brief. When I called her to plan another play date for the boys, she told me that she didn't think we could do that because she didn't want her son to "catch" my son's CP. I hung up and cried.
- A series of free, downloadable short videos in which people with disabilities and their families discuss their experiences seeking access to and receiving healthcare, available at: <http://www.dredf.org/healthcare-stories/>

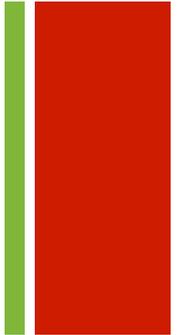
# + Barriers: Provider Training

- A provider suggested a woman in her 50s with DD only visit once a year as “She’s lived a good life - once a year is fine”
- A provider while delivering said of mom “Well, the Deaf woman should tie her tubes so she doesn’t get pregnant again”
- “Patients with mental retardation do not feel pain and therefore do not need anesthesia”
- Some individuals with disabilities suggest that some doctors, under the misguided belief that the only acceptable outcome of treatment should be cure, distance themselves from their patients with disabilities because they represent treatment failures in some way. . . . both adult and pediatric primary care providers tended not to refer their patients with disabilities for [early detection and prevention] services unless they are directly related to their individual disabilities



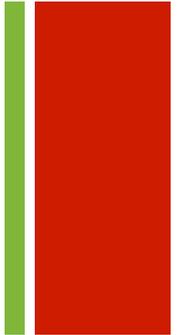
# + Barriers: Research and Monitoring

- Insufficient progress in imbedding a standard set of questions to identify disability status in healthcare reporting tools, including health information technology (HIT) and Exchange data requirements
- Insufficient knowledge about where people with disabilities seek care, the quality of the care received, and the effectiveness and accessibility of that care
- Insufficient progress in developing and testing quality measures of home and community-based long-term services and supports, not just clinical quality measures
- Failure to recognize people with disabilities as an underserved population, and to fully integrate disability within broader HHS and public health measures to combat health disparities





# A Minority Problem

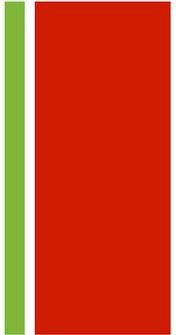


The IOM noted in 2007 that:

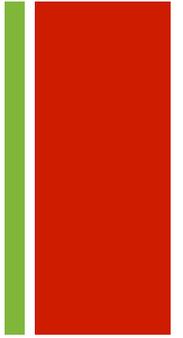
Today, between 40 million and 50 million people in the US report some kind of disability. That number will likely grow significantly in the next 30 years as the baby boom generation enters late life, when the risk of disability is the highest. If one considers people who now have disabilities (at least 1 in 7 Americans), people who are likely to develop disabilities in the future, and people who are or who will be affected by the disabilities of family members and others close to them, then disability affects today or will affect tomorrow the lives of most Americans. Clearly, disability is not a minority issue.

# + Specific Advocacy Points

- HHS has completed a draft action plan to reduce disability health disparities, written by CDC, that was due to be released in 2012 but has not been. Its release would reinforce the urgency and importance of disability status data collection
- Fully include the collection of disability status demographic information within HIT tools and all other data requirements mandated under the ACA
- Incentivize providers with disabilities as a disparity reduction measure
- Reorient away from an acute care system toward a sustainable system of chronic care and independent community living



# Hope for the Future



Details matter, and the particular expertise that we all have in specific populations that experience health and healthcare disparities is invaluable. Nonetheless, we cannot hope to create a fully inclusive and truly effective healthcare system for **all** individuals until we can work together for every person whose health is unfairly compromised because of a personal characteristic such as race, ethnicity, disability, gender, sexual orientation or identity, or a diverse combination of characteristics.