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Remarks for ICDR Public Comment Meeting, Aug. 13, 2008

I would like to thank the Interagency Committee on Disability Research for this opportunity to speak on existing federal research programs and the direction of future disability research.

The Disability Rights Education and Defense Fund (DREDF), founded in 1979, is a leading national civil rights law and policy center dedicated to advancing and protecting the interests of children and adults with disabilities. DREDF's work is dedicated to activities that promote integration of people with disabilities into the mainstream of society. We specialize in federal disability nondiscrimination laws, including Section 504 of the Rehabilitation Act of 1973, prohibiting disability-based discrimination by recipients of federal funds; P.L. 940-142, the Individuals with Disabilities Education Act of 1975 (IDEA), guaranteeing appropriate education services in the "least restrictive environment" for children with disabilities; the Fair Housing Amendments Act of 1988 (FHAA); and the Americans with Disabilities Act of 1990 (ADA). While our work encompasses many of the research areas that ICDR has listed in the notification of this public meeting, such as employment of people with disabilities, community integration and services, accessible transportation, assistive technology, and a broad conception of universal design, I will be addressing primarily the issue of health disparities today.

DREDF increasingly has become involved in the area of healthcare access over the past several years from both a policy and litigation standpoint. Frankly, the many pronged and persistent nature of healthcare inaccessibility, from the physical inaccessibility of provider offices to a lack of universally designed examination and diagnostic equipment to the pervasive absence of alternative communication formats, sign language interpreters and programmatic accommodation, demands redress through as many tools as possible.

As a law and advocacy organization, DREDF has long advanced the "social model" of disability, whereby disability is not simply the presence of an impairment or health condition in an individual, but a function of the complex interplay between the individual and his or her surrounding physical, social, cultural and economic environment. It is equally our understanding and conviction that "disability" is neither a health outcome in itself, nor a status that is inevitably associated with poor health. Rather disability is a demographic characteristic akin to such other characteristics as age, sex and race. As such, the U.S. population with and without this demographic characteristic should equally be analyzed for correlation with health status, health risk factors, the prevalence of secondary health conditions, and access to care and preventative services, as well as other socio-economic characteristics such as education, income and employment.

We have been following with great interest the growing recognition in myriad federal programs and institutions that there is inadequate information concerning the health and quality of life of people with disabilities, insufficient analyses of the information that exists, and consequently great difficulty in assessing whether federal programs are successfully serving the needs of people with disabilities. Notable in the last few years:

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- *Healthy People 2010*, which called for the inclusion of disability status as a characteristic that should be monitored for disparities in over 100 of the 467 objectives that the comprehensive national health promotion and disease prevention initiative establishes for improving the health of all people in the U.S.¹;
- A 2003 conference sponsored by the ARC of the United States² at which 12 separate federal agencies, including the U.S. Department of Health and Human Services and the Department of Education, agreed on the need to develop a research agenda that would advance participation and community integration for people with intellectual and developmental disabilities;
- The Surgeon General's 2005 *Call to Action to Improve the Health and Wellness of Persons with Disabilities* which recognized that people with disabilities have the potential to lead lengthy, productive and healthy lives, and promoted healthcare professionals' treatment of the whole person and people with disabilities' capacity to maintain independence through healthy lifestyles;
- The Government Accountability Office's (GAO) 2005 review of 200 federal programs housed in 20 agencies that serve persons with disabilities identified the need for critical change in many of the programs reviewed, and led to a forum in 2007 on modernizing disability programs where participants agreed that the success of such programs should be measured not only through such economic measures as program participants' income and employment, but also their quality of life;
- An April 2008 report issued by the National Council of Disability entitled *Keeping Track: National Disability Status and Program Performance Indicators* which pinpointed "significant knowledge gaps" in federal data collection concerning people with disabilities, and recommended the adoption of a set of social indicators that could be used to holistically measure the lives and progress of people with disabilities over time;
- A June 4, 2008 hearing of the U.S. Representatives' Committee on Oversight and Government Reform which examined the Federal Government's efforts to collect reliable data for the evaluation of disability policy and the measurement of the quality of life of people with disabilities³;
- A very recent July 2008 report issued by the National Center for Health Statistics on *Disability and Health in the United States, 2001-2005*, that uses data from the National Health Interview Survey (NHIS) to devise a consistent measure of disability. This measure is then consistently and thoughtfully applied to a large number of indicators typically used to track health disparities (e.g., exercise, obesity, smoking, alcohol use, usual source of care, health insurance, mammograms, etc.) to present a comparative picture of the health status of working age adults with and without disabilities.

¹ The 100 objectives that called for disability to be monitored for disparities is in addition to those objectives framed within "Disability and Secondary Conditions," which was one of Healthy People 2010's specific focus areas.

² A leading grassroots organization comprised of people with intellectual and developmental disabilities and their families and advocates.

³ The Office of Management and Budget (OMB) issued a July 24, 2008 reply to the Oversight Committee's June 12, 2008 letter with requests based on the witness recommendations made at the hearing. The OMB letter specified that a series of disability questions currently in the American Community Survey is being included in the Current Population Survey, the National Crime Victimization Survey, and the National Health Interview Survey, and the OMB will recommend the inclusion of the series on the American Housing Survey as well. The letter also suggested that the series would be considered for inclusion in one of the three remaining major national surveys that is currently undergoing redesign, but that the other two remaining surveys already contained more specific and specialized questions pertaining to disability. This response does not address the difficulty of cross-tabulating information across surveys that have different baseline measures and definitions relating to disability.

DREDF agrees with the conclusions and recommendation of many of the above meetings and reports. In particular, we strongly agree that disability must be included as a subgroup characteristic within the larger Key National Indicators Initiative (KNII) being developed by the National Academies and the Government Accountability Office. A more holistic set of indicators on the lives of people with disabilities must be developed and broadly disseminated, and encompass social indicators that measure various aspects of life important to people with disabilities, including access to healthcare and health maintenance. Ongoing work on a baseline definition or measure of disability that can be used across survey instruments must continue, and federal agencies must work together to develop and promote a standard set of disability-related questions that will enable information and results to be compared across different instruments.

The 2008 National Center on Health Statistics' recent in-depth report on disability and health in the U.S. is an example of the type of work that can be derived from existing information and survey sources when sufficiently funded and thoughtfully designed. More analyses of this nature are needed. Some surveys, such as the Medical Expenditure Panel Survey sponsored by the Agency for Healthcare Research and Quality, is meant to be nationally representative and currently over sample blacks, Asians, and Hispanics, and on occasion other population groups, in order to focus on a particular policy question of interest. People with disabilities, and especially smaller population sub-groups of people with specific disabilities for whom little statistically reliable information currently exists (e.g., children who are hearing impaired or deaf), can also be over sampled to derive more needed information. Similarly, federal survey instruments and their design must begin to address the need for cross-tabulation of race and ethnicity with disability status so that all stakeholder groups can begin to identify and address the often unique needs of those within the disability community who come from diverse racial or ethnic backgrounds.

Finally, the questions asked in all national federal surveys must go beyond the treatment of disability as an individual medical condition or health outcome to reach into the actual systemic healthcare experiences of people with disabilities. To this end, we need questions that raise some of the specific barriers that people with various disabilities encounter in healthcare, such as: (i) the physical inaccessibility of provider offices or diagnostic equipment, (ii) a lack of needed communication modes such as Braille or sign language, (iii) ignorance about the need for accommodations in office procedures, (iv) lack of clinical competence in how one's disability-related needs interact with particular and often common procedures, (v) the unavailability of paratransit, or (vi) a need for case management across primary care and specialty practices that is not reimbursed by insurance.

We recognize that in some ways, it is easy for us to ask for these things. We are advocates, not statistical experts, and we are not the ones who will be designing the questions. On the other hand, we are the ones who continue to live with the consequences of the *lack* of information over time about the lives and health experiences of people with disabilities. We are intimately familiar with the impact in the lives of our community when there are unequal opportunities for quality healthcare. Without federal data to support the existence of disparities among the population of people with disabilities in terms of health quality, outcomes, access, cost, or use of or satisfaction with health care services as compared with the general population, it remains all too easy for poor health among people with disabilities to be simply and entirely attributed to the mere presence of disability. The 2000 Minority Health and Health Disparities Research and Education Act of 2000 (P.L. 106-525) defines a "health disparity population" as one in which

“there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population.” People with disabilities have generally not been included in this legislation’s research and funding mandate, and we suspect that this is due in large part to assumptions about disability and health status that are perhaps not supported by scientific evidence, but also not clearly refuted by existing data and analysis. Once again, people with disabilities are on the outside looking in. And once again, the community will do the work it needs to do to be included, but our federal agencies and programs must support our efforts. Thank you.