

***Written Testimony  
Of  
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***Information Policy, Census, and National Archives Subcommittee  
Oversight and Government Reform Committee  
Wednesday, June 4, 2008  
2157 Rayburn HOB  
2:00 p.m.***

As a person who has been severely visually impaired coupled with two major chronic disorders for approximately 30 years, worked in a variety of professions and settings, lived in several states in different regions of the country, served on boards, committees, task forces, researched published referred articles, and founded several organizations that focus on persons with chronic illnesses and disabilities, I bring a varied opinion and approach to this all important and necessary topic.

After a thorough review of the National Council on Disability Report entitled “Keeping Track: National Disability Status and Program Performance Indicators, April 21, 2008, I support the conclusions and recommendations. The answer to the presented question “Does Federal Statistical Data Adequately Serve People Living with Disabilities?” is a resounding “NO.” Some of the challenges are because of some of the reasons cited in the 2008 Report.

Today, there is a group of individuals living with disabilities that are not on any federal, state, or local rolls (or in local, state, federal agency/system) that would collect information necessary to identify indicators needed to determine their quality of life. There are subpopulations within the disability population who have received or who have not been included in past data collection processes, adequately or not at all. They are referred to as the “hard-to-count” subpopulation within the disability population. Some of those subgroups include persons of minority racial/ethnic cultures, women with disabilities, women of color with disabilities, homeless with disabilities, individuals with disabilities in the rural areas, individuals with disabilities who are unfamiliar with programs and services or who are suspicious of programs and services.

Strategic exploration should be a part of this review process to find these individuals with disabilities to secure crucial data. Options for collecting information must include a myriad of methods, both traditional and modern. The traditional approached still have there place and will appropriate in many situations; however, they will need to be strengthen and revised to meet the needs of this ever changing population that we are interested in securing information from in order to better serve individuals living with disabilities. Some of the traditional methods of collecting information are when individuals with disabilities sign up for services that are administered by a variety of programs under the auspices of local, state, and federal agencies, for-profit organizations, not-for-profit organizations, and private entities. Also, information is collected through

disability advocacy organizations, town hall meetings, focus groups, roundtable discussions using survey questionnaires, and ratings scales, etc. Information can be collected at selected disability specific and general disability conferences, seminars, workshops, trainings, support group meetings, etc. Traditional methods include door-to-door, face-to-face interviews, telephone interviews visiting persons in their homes, churches, community centers, and cultural gathering events. Collection of information must be accessible and developed in a variety of formats; regular print, large print, Braille, voice activated, interpreters, illiterate, etc. In addition, there are a variety of methods that be developed to collect information using technology. This information must be collected from subjective methods, objective methods and other standardized and economic indices.

It is vital that a Coalition is created to further explore these conclusions and recommendations, as well as examining some additional suggestions. The composition of the Coalition must be diverse and representative of the individuals who make policies, those who study/teach policies, those who implement/apply policies and those who benefit from the policies; policy-makers, academicians, practitioners, persons with a variety of disabilities and advocates from a variety of local, state, and national organizations that focus on multicultural disabilities issue (i.e. National Association of Multicultural Rehabilitation Concerns), who could bring forth the needed results. Also, it is essential that the diversity and representation be as inclusive as possible; including being “demographic sensitive” to address the following: age, sex, racial/ethnic affiliate, education, socio-economic, geographical region (urban, rural, etc.), diverse disabilities, temporary/permanent, acute/chronic disorders, onset of disability, different stages of disabilities, congenital/developmental, cultural beliefs/practices, religious/spiritual doctrine, volunteerism, avocational activities, hobbies, advocacy/activist activities, taking care of one’s self, historical context in the United States, etc.

This Coalition must do more than develop a fuller set of indicators that are important to people living with disabilities and ensure that disability is included as a subgroup characteristic; but it must over see and review every instrument that is used by any entities that receives or will apply to receive federal funding or recognition of some sort of federal association/affiliate. There must be some type of mandate that these entities must ascribe to and sign an agreement. Also, this Coalition must oversee, audit, investigate and determine if these entities are following government regulations. In addition, any developed instrument must be approved by this governing body with an annual report submitted each year with a copy of all instruments used to collect data. There should be some penalties in place if entities fail to comply. Finally, this Coalition should establish a “clearinghouse” where all of this data can be retrieved of links can be created, so that can obtain. With the standardization process, policies, guidelines and assistance with instrument development data, should be more readily accessible with consistent and appropriate interpretation, application, usefulness and meaning.

In order to develop instruments that will assess accurate and adequate information about the “quality of life” for individuals living with disabilities, these individuals living with disabilities must be assessed in a variety of ways using a variety of instruments in various

settings. There are many indicators that influence the quality of life for people with disabilities and we are aware there will be multiple indicators. However, it is imperative that we identify those indicators and place them along a continuum that will allow those designing assessment instruments to reflect those indicators to collect the most adequate and meaningful data, possible. To determine which indicators (social, topical, and performance) are to become a part of the many instruments that are to be created and used to collect data, there must be guidelines and an outlined process. The identified indicators must have meaning and be meaningful to people living with disabilities that are participating in the collection of this requested information. The Coalition should identify all of the federal, state and local agencies/institutions that offer programs and services that people without and with disabilities could possibly need/want. Also, the establishments of a Committee with the duties and responsibilities to oversee, assist, and enforce the flexible standardization, compatibility, and consistency of any instrument used. In order to identify and measure indicators that reveal information about the quality of life, including people living with disabilities, both qualitative and quantitative data must be collected. .

The functional description of the term ‘disability’ is a cornerstone of adequately measuring the quality of life of people living with a disability. As a professor and a person with a disability, the “definition” has always troubled and frustrated me. It never seemed to capture the essence of “what a disability” is means. This term is so encompassing and complex that to define it as it has been, in general terms, reduces it to a very narrow and somewhat skewed concept with a confusing and limited denotation. Therefore, this problematic definition negatively influences policies relevant to disability issues/concerns, development of instruments, collection of data, interpretation of data, dissemination and application of information, which may be inadequate and incorrect. In order to answer the broad question regarding adequate data collection that can be quantified and then expressed in “quality of life” terms, the word “disability must become a description, which can be translated into a meaningful functional application, regardless of who or which agencies or institutions (i.e., healthcare, housing, food, transportation, education, architectural and structural, etc.) is using it. This description also has to include aspects that sensitive to cultural issues in a diverse society that is present and ever growing in the United States. We must stay ahead of growth and plan for the future and be ready for the future becomes the present; always evaluating and re-evaluating for the present-future.

When the concept of disability is written as a description with expanded and inclusive information and criteria, then it becomes a functional definition that can be used across agencies on federal, state, and local levels to be inserted in all instruments that are designed to measure issues relevant to people with disabilities, as a subpopulation, within the general population. This concept can not be limited and narrowly focused with the final indicator measure being “a job, consistent work, or gainfully employed.” The concept must move along a spectrum of indicators with varying dimensional aspects addressed and included. If we are truly serious about this functional description for the term disability, the Coalition will need to examine every definition/description it can find

and determine if it belongs and if it does, where it should be located along the spectrum of the description.

Quality of life can be more adequately determined when the above mentioned items are developed, integrated, and implemented with policy guidelines designed to assist the process of collection and interpretation that has flexibility with uniformity.