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**BEFORE THE  
SUBCOMMITTEE ON INFORMATION POLICY, CENSUS, AND NATIONAL  
ARCHIVES  
OF THE  
COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM  
UNITED STATES HOUSE OF REPRESENTATIVES**

**HEARING ON: Does Federal Statistical Data Adequately Serve People Living with  
Disabilities?  
June 04, 2008, 2:00 PM**

It is my honor to stand-in for Dr. David B. Gray as a witness at this hearing. By most measures, Dr. Gray would have values comparable to a very successful person. He is a recognized researcher at the highest ranked occupational therapy program in the country. Before joining the faculty of Washington University, he was a presidential appointee and Director of the National Institute of Disability Rehabilitation and Research. He is a family man with three grown children and two grandchildren. It is because of a, several times delayed, visit to his grandchildren that he is not here today. For many of the objective measures of ‘quality of life’, Dr. Gray would exceed national averages on income, education, social economic status, housing, neighborhood, and transportation. By many objective measures of society, Dr. Gray is far below national standards. Because of an accident, Dr. Gray is a quadriplegic, which is, according to the dictionary, a person who is permanently unable to move his arms or legs. He does have some arm movement and with the aid of assistive technology devices, he is able to feed himself, drive an adaptive vehicle, and use a computer. On medical model measures such as the Functional Independence Measure (FIM) or the SF 36 Health Assessment tool, Dr. Gray would score poorly.

Medical model measures are meant to assess capacity, the ability to perform a function. These measures are what people ‘can do’ in clinical settings. For example, Dr. Gray would score a one (performs less than 25 percent of the task) on the FIM item number 5, Dressing Lower Body, that person could not dress himself. The logical extension of this assessment is that this person could not leave his house to go to work unless he had assistance to get dressed. Clearly work is important to Dr. Gray and others with disabilities. The gap in our understanding of why some people with disabilities work while most do not requires that we move beyond the ‘can do’ measures to a holistic, social model of disability.

Using a social model of disability, assessment has a focus on what people with disabilities do and the factors that help them do the activities. These measures assess what people with disabilities do and what their quality of participation is in activities in their daily lives, not their health-related quality of life. The construct of full participation includes the evaluation of their engagement in activities that they feel are important, the degree of choice (when, where or how, they do the activity), and the satisfaction the person derives from their participation. The social model postulates that environmental context can create barriers or facilitators to participation by people with disabilities. A full understanding of disability then requires that the context where participation occurs or does not occur be thoroughly examined.

Using this approach, service programs will be able to determine what facilitators are useful to improve participation in specific activities. For example, our work with Paraquad, a Federally funded large independent living center in St. Louis, has shown that outcome measures are needed that focus on the specific and general goals of the services offered. The Olmsted Supreme Court decision that supported the right of people with disabilities to choose where they live resulted in many state Medicaid programs funding consumer directed personal assistance services. Those eligible must meet a means test and have one or more impairments that are related to their inability to perform their own personal care activities. This program is not based on any specific medical diagnosis but rather a lack of ability to perform specific tasks. To examine the effects of this program, we asked consumers to answer questions on the quality of the services (number of days missed; times the attendant was late, choice and satisfaction with the attendant and the importance of the help provided. To assess the influence of the personal assistant services on the consumers' quality of participation, we asked those receiving the services if they participated in community activities more often and how they evaluated their participation. Measuring the effectiveness of the consumer directed personal assistant program requires establishing an initial level of consumer participation for use in comparison with participation while the services are being delivered.

Another example of establishing outcome measures to gauge program services is the Paraquad program that provides recycled assistive devices to people with mobility and other impairments, again the eligibility is need not diagnosis. The outcome measures developed to examine this program's effectiveness included establishing an initial baseline of participation in a variety of activities both in the home and in the community. After the consumers were matched to a device and trained in the use of the device, they were provided the device. After one month, the consumer was ask to answer a telephone survey that included question on the use of their equipment and on their participation in activities at home in their communities.

The take home lesson from our experiences in the use of outcome measures is that they need to include questions on the specific program services as well as the broader effects on the consumer's community participation. Such measures require establishing baselines and frequent subsequent assessments to provide meaningful information to examine program effectiveness.

Most of the Federal Statistical Data is demographic and normative. Federal agencies report the number of people with disabilities that are eligible for or enrolled in their services and can cite what the proportion of the eligible for services is to the general population. However, Federal disability data collection is inadequate to identify the dynamics of disability. Federal disability statistics are largely derived from household surveys and individual-level administrative records. As a result, the vast majority of research and policy discussions derived from these data treat disability as a one dimensional personal phenomenon, ignoring the environmental components of disability. For example, we have no idea how many buildings and transportation systems are accessible, not to mention Section 8 housing facilities.

The existing data cannot be used to show a relationship between service provision and a beneficial change in the lives of people with disabilities. To assess change criterion based assessment are needed rather than status relative to the general population. To report that the unemployment rate of people with disabilities has remained stable while the same rate for the general population has risen might be a misleading indicator of beneficial change based on a normative criterion. However, if assessment of change is criterion referenced, then one might evaluate progress differently. With a criterion-referenced measure, the observation that over 60 percent of the people with disabilities have been unemployed for a year does not meet a stated goal of reducing unemployment to 40 percent.

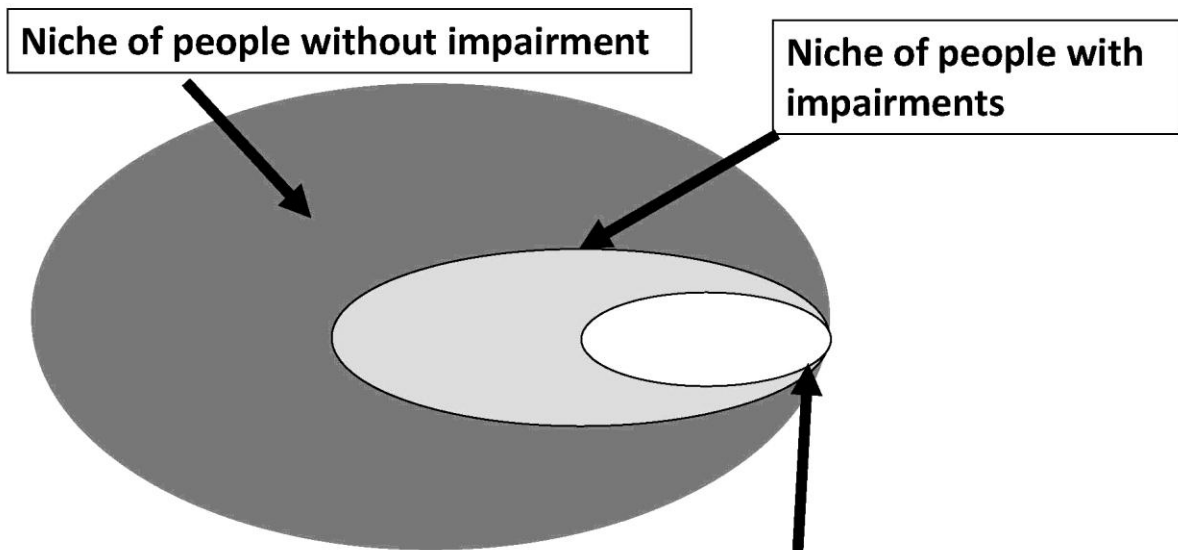
Another consideration is that many people consider disability to be a one-dimensional construct. As an example, the level of disability of a person is often based on whether a person can or cannot do an activity such as dressing, bathing or toileting. According to the World Health Organization's International Classification of Functioning, Disability and Health (ICF) disability is an umbrella term for impairments, activity limitations, and participation restrictions.

The framework of the ICF for measuring health and disability is to include data on both individual and population levels. The ICF defines activity as the execution of a task by an individual. Activity limitations are difficulties an individual may have in executing activities. ICF further defines participation as involvement in a life situation and participation restrictions are problems an individual may experience in the involvement in life situations. The aggregate of tasks define a life situation. Employment would be considered a life situation defined by the tasks or duties of the job. The participation in employment may be restricted by lack of transportation, accessible environment, or education and training. The key to understanding disability requires the examination of interventions that enhance the individual's capacity to do activities and the implementation of environmental facilitators that result in the full participation of people with disabilities in their homes and communities.

In summary, we would like to offer three suggestions to improve the adequacy of data that serve people with disabilities.

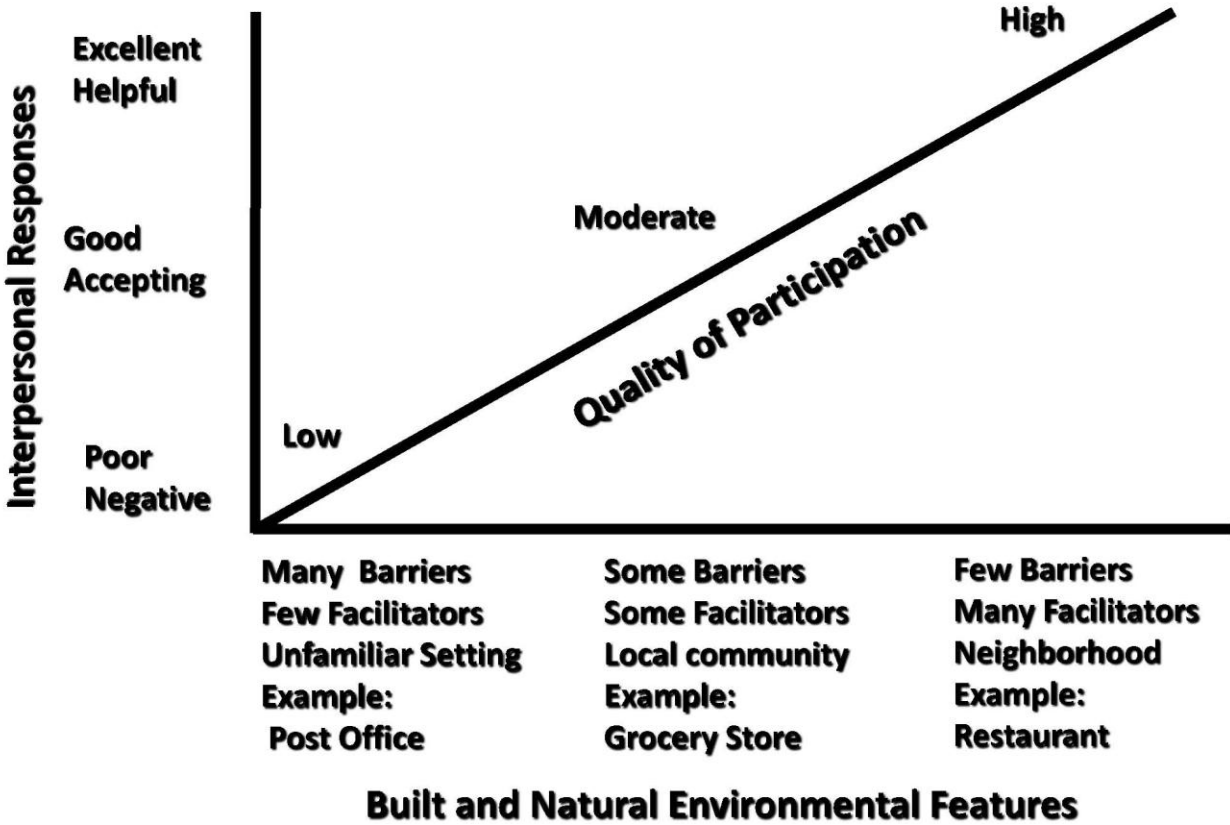
1. One of the most often used national surveys is the National Health Interview Survey (NHIS). I recommend that this survey be modified and reissued. Adding the diagnostic categories will allow this function based survey to be linked to the ICF. Adding questions on participation and environmental context will also link this survey to the ICF.
2. Data used for program evaluation should be criterion-referenced based on the goals of a program. The evaluation of progress should be referenced to valid and reliable baseline measures. After implementation of program services, subsequent assessments can establish program effectiveness.
3. Data used to assess people with disabilities should be multi-dimensional using scales that span the barriers and facilitators to full participation, a tenet of the American with Disabilities Act. Compliance with this tenet mandates the measurement of a variety of dimensions of disability including capacity, participation and environmental context.

**Social Ecology of People with Mobility Impairments : Ecological  
Niche of Sub-Species  
(see also Charles Darwin)**



**Niche of people with impairments is limited immediately post discharge from rehabilitation without solutions (AT, PAS, Education, Transportation, Housing and Accessible/receptive environments)**

# Community Receptivity & Participation Model



## Can and Do Do

**CAN DO ACTIVITY  
TEST – ROM, FIM**

**CAN NOT DO ACTIVITY  
TEST – ROM, FIM**

**DO DO  
Participation  
in Context  
PARTS SPARC**

**A. Capacity to Do  
Activity AND Does  
Participate  
+ / +**

**B. No Capacity to Do Activity  
BUT Does Participate  
- / +  
WHAT MAKES THE  
DIFFERENCE? – Service  
provision – Devices,  
Assistance, Transportation**

**DO NOT DO  
No  
Participation  
in Context  
PARTS SPARC**

**C. Capacity to Do Activity  
BUT Does Not Participate  
+ / -  
WHAT MAKES THE  
DIFFERENCE? – Service  
provision – Devices,  
Assistance, Transportation**

**D. No Capacity to Do Activity  
and Does Not Participate  
- / -**