However, as people age, one of the most significant problems that they face is the presence of a disability. For example, loss of vision and hearing become more prevalent with aging, affecting millions of Americans. When either of these disabilities is already present, the onset of a secondary disability is especially problematic, particularly when the individual is faced with additional age-related disabilities.

One-third of persons over 65 years of age have a hearing loss sufficient to interfere with speech perception, and the prevalence rises with increasing age (*A Report of the Task Force on the National Strategic Research Plan*, NIDCD, 1989). There is also a growing number of under-served individuals with a combination of multiple sensory, physical, and cognitive impairments (Malakpa S., *Job placement of blind and visually impaired people with additional disabilities*, RE: View, Vol. 26, pgs. 67–77, 1994).

Low vision or blindness frequently coexists with other disabilities including hearing loss, cognitive impairments, and mobility limitations. Individuals with multiple disabilities present technological challenges and require complex adjustments to achieve functionality in and across environments (Greenbaum, et al., *Use of motorized wheelchair in conjunction with a guide dog for legally blind and disabled*, Archives of Physical Medicine and Rehabilitation, Vol. 79(2), pgs. 216–217, 1998). Functional status is diminished for sensory impaired subjects. Combined vision and hearing impairments have greater effect on function than single sensory impairments and influence functional status independent of mental status and co-morbid illness. For example, blind people who acquire significant hearing problems have the core of their already constrained communication system threatened. Persons with significant hearing loss, who lose visual acuity, are equally affected. Overall, this suggests that interventions to improve sensory function may improve functional independence (Keller, et al., *The effect of visual and hearing impairment on functional status*, Journal of Geriatric Sociology, 47(11), pgs. 1319–25, 1999).

Data from the Survey of Income and Program Participation (SIPP), 1997, indicate that 3.9 million (12.1 percent) persons age 65 and older had difficulty seeing the words and letters in newspapers even when wearing glasses or contact lenses; of that group, 1.1 million (3.3 percent) were unable to see the words and letters at all, while 2.8 million (8.8 percent) had visual problems that were not severe. The SIPP also measures hearing problems. Even when wearing a hearing aid, 4.3 million (13.4 percent) had difficulty hearing normal conversation. Of that group, about 500,000 (1.5 percent) were unable to hear what was said in normal conversation while about 3.8 million (11.9 percent) had hearing problems that were not severe.

The number of individuals with both severe hearing and visual impairments (deaf-blind) is small. But, just as the number of elders will be growing in absolute numbers and as an increasing proportion of the population, the number of elders experiencing severe sensory loss is likely to increase as well (Crews John E., *Aging and Disability: The issues for 1990's*, In Boone (ed.): Challenge to Independence, pgs. 47–59, U. Arkansas Press, Little Rock, AR, 1998). The greatest challenges faced by multiple sensory impaired people are an absence of functional communication modes and access to information technology. Unlike individuals who, blind from an early age, learned Braille as part of their developmental language in special classes or in institutions for the blind, people who lose their vision in adulthood rarely master Braille for communication purposes. To date, technologies for such people have focused primarily on tactile interpreting for face-to-face communication (Engleman, et al., *Deaf-blindness and communication: Practical knowledge and strategies*, Journal of Visual Impairment and Blindness, Vol. 92(11) pgs. 783–798, 1999).

In a recent report on data from the National Health Interview Survey (NHIS) study, Campbell, Mority, Zack and Blackman (1999) determined that older adults who reported vision and hearing impairments were two times more likely than their peers without impairments to report difficulty walking (48.3 percent vs. 22.2 percent), three times more likely to report difficulty getting outside (32.8 percent vs. 11.9 percent), and almost 2.5 times more likely to report difficulty getting into or out of bed or a chair (25.0 percent vs. 10.4 percent). In addition, older adults who experience both vision and hearing impairments were three times more likely than their peers without impairments to report difficulty preparing meals (20.7 percent vs. 7.8 percent) and more likely to report difficulty managing medication (13.4 percent vs. 5.0 percent).

Furthermore, older adults who reported both vision and hearing loss were more likely than those without either vision or hearing impairments to have: (a) fallen during the preceding year (37.4 percent vs. 19.8 percent), (b) broken a hip (7.6 percent vs. 4.5 percent), (c) reported a higher prevalence of hypertension (53.4 percent vs. 44.3 percent), (d) reported heart disease (32.2 percent vs. 20.6 percent), or (e) are twice as likely to experience a stroke (17.4 percent vs. 7.3 percent) (Campbell, et al., (*Surveillance for Sensory Impaired, Activity Limitations, and Health-Related Quality of Life Among Older Adults*, NHIS, National Center for Environmental Health, 1999).

Untangling the relationships among sensory loss, co-morbidities and secondary conditions, and activity limitations poses an important challenge for public health, the development of public policy, vocational rehabilitation service providers, community integration efforts, and fulfillment of the NFI. For example, the relation between sensory limitations and activity limitations is not clearly understood, more information is needed about the relation between underlying conditions, activity limitations, and secondary conditions (Campbell, 1999).

In order to further our understanding of co-morbidity, studies that examine community planning efforts for housing and transportation, the effect of policy and planning efforts on the integration of older persons with vision and hearing problems into the community, and the influence of sensory and activity limitations in aging populations on rehabilitation outcomes are crucial. Finally, more information is needed regarding strategies that many older adults, who have a vision and hearing disability, employ to sustain participation in the community.

Priority 1

The Assistant Secretary proposes to establish a Disability and Rehabilitation Research Project on Persons Aging with Hearing and Vision Loss. The purpose of this absolute priority is to explore ways to improve outcomes for persons who are blind or who are deaf and who are now experiencing a secondary onset of hearing loss or vision impairment resulting from aging. The DRRP will conduct research, development, training, and dissemination activities and evaluate model approaches for improving employment and community integration options, including more viable communication systems, for such individuals who are 55 years of age, or older. In carrying out this purpose the DRRP must:

(1) Investigate the prevalence of age-related onset of deafness among older American blind individuals and age-

related onset of blindness among older American deaf individuals and the impact on the employment and community integration options, including more viable communication systems for each population;

(2) Identify and evaluate technology and service delivery options, such as transportation, housing, and community integration activities for individuals with early onset deafness or blindness and late onset hearing or vision loss and their effectiveness with persons experiencing secondary sensory loss resulting from aging;

(3) Identify and evaluate access to use of technologies, including assistive devices and telecommunication or other existing communication systems, such as tactile interpreter support, needed to assist persons with early onset deafness or blindness and late onset hearing or vision loss and their effectiveness with persons experiencing secondary sensory loss resulting from aging; and

(4) Using available dissemination mechanisms, with appropriate assistive technical modification, disseminate findings, and develop strategies to educate both consumers and providers, especially vocational rehabilitation workers, in use of these techniques.

In addition, the DRRP must:

- Coordinate the efforts of this DRRP with other NIDRR, Office of Special Education Programs (OSEP), and Rehabilitation Services Administration (RSA) projects that address related activities such as Blindness, Deafness, Deaf-Blind, Aging, Accessible Housing, Accessible Transportation, Telecommunication, Independent Living, and Interpreter Training programs;
- Solicit direct input from stakeholders (e.g., persons who are deaf, blind, and deaf-blind; service providers; and employers) as part of the ongoing planning, development, and implementation of the DRRP's research activities;
- Demonstrate efforts to secure supplementary funding that will permit the DRRP more latitude in exploring additional related studies, in addition to the Federal monies available from this NIDRR grant; and
- Identify and investigate a study population that includes a balanced sample of subjects representative of national demographics.

Evaluation of the Changing Universe of Disability and Systems Change Activities

Background

Demographic, social and environmental trends affect the prevalence and distribution of various types of disabilities as well as the demands of those disabilities on social policy and service systems. Past studies related to the changing universe of disability have included, as one focus, those which can be identified on the basis of changing etiologies for existing disabilities, or the appearance of new disabilities.

The changing universe of disability also refers to broader changes such as growth in segments of the population with higher prevalence rates for certain disabilities and the consequences of changes in public policy, health care services, and medical and assistive technologies. At the present time, significant policy changes at the Federal level and implementation of those policies promise a substantial and progressive impact on the provision of various services and supports to all people with disabilities. Recent major policy developments include the Supreme Court's Olmstead decision, the New Freedom Initiative (NFI), and the Workforce Investment Act (WIA).

These new policies may provide additional opportunities for people with significant disabilities to remain in or enter the workplace, to live within the community, and to have increased access to assistive technologies. Development of plans to evaluate and monitor the course of these policies over time is critical for understanding the impact of systems change activities on the changing universe of disability. Such assessment requires the identification or development of appropriate sources of data and the analytic work required to identify the implications of policy changes for financing of, access to, and use of home- and community-based long-term care services, rehabilitation systems including vocational rehabilitation, and assistive technologies on a highly dynamic population.

NIDRR-funded research on the changing universe of disabilities has assisted with better understanding of factors such as new etiologies, as mentioned earlier. In their early writing on the topic, Seelman and Sweeney had postulated that ''poverty is the primary screening indicator of the many variables that increase the risk of disability (Seelman K., and Sweeney S., The Changing Universe of Disability, *American Rehabilitation,* Autumn-Winter 1995).'' Subsequent analyses of relationships between poverty and disability have identified factors, such as access to health care, where one lives, and exposure to environmental risks, that influence prevalence and distribution (Fujiura G., Quality of Life and the Poverty Agenda; Emergent Disability in America, In press, 2000; Fujiura G., Yamaki K., Czechowicz S., Disability Among Ethnic and Racial Minorities in the United States, *Journal of Disability Policy Studies,* Issue 9, 1998). In identifying an array of factors associated with the ''changing causes and patterns of disabilities,'' one must also address ''the disability related consequences, including functional loss, employment, and social behavior (Seelman and Sweeney, 1995).'' Ultimately, the researcher must carefully focus on evaluation of the impact of policy or systems change while controlling for the range of other variables that affect disabilities, including those factors that are unique to underserved and unserved populations. With a carefully constructed analytic framework, research can address the paucity of information about the degree to which rehabilitation services are provided to unserved or underserved populations, within the context of the changing universe of disability. In addition, studies can illuminate how policies and systems change influence access, usage, and rehabilitation service outcomes for these populations.

Priority 2

The Assistant Secretary proposes to establish a Disability and Rehabilitation Research Project on the Evaluation of the Changing Universe of Disability and Systems Change Activities. The purpose of the proposed absolute priority is to evaluate the implications over time of systems change activities for populations within the changing universe of disability. The DRRP must:

(1) Identify and evaluate existing or proposed data systems that can be used to monitor systems change activities at the State or Federal level or both, including policy changes related to the NFI, the WIA, and the Olmstead decision;

(2) Identify, evaluate, and project the impact of systems change activities and new policies for people with newly emergent disabilities or changing manifestations of disability or both, including those who are unserved and underserved;

(3) Develop proposals for new systems or data variables, or changes, as necessary, to existing data systems that will facilitate use of such data to eliminate gaps in the availability of mechanisms to monitor the impact of systems change activities on people with newly emergent disabilities or changing manifestations of disability or both, including those who are unserved and underserved;

(4) Disseminate findings and recommendations to modify monitoring data systems or to institute new monitoring approaches; and

(5) Conduct research to identify and evaluate the implications of policy changes or other systems change activities on public and private rehabilitation programs and services for persons with newly emergent disabilities or changing manifestations of disability or both, including those who are unserved and underserved.

In carrying out these purposes the applicant must:

- Involve consumers or their families, as appropriate, in all stages of the research and demonstration endeavor;
- Demonstrate culturally appropriate and sensitive methods of data collection, measurements, and dissemination addressing needs of individuals with disabilities from diverse backgrounds;
- By the end of the fourth year, convene a national conference to disseminate and discuss information about the affect of systems change activities on persons with newly emergent disabilities or changing manifestations of disability or both including those who are unserved and underserved and proposals to address gaps in such activities; and
- Serve as a resource to researchers, consumers and consumer groups, planners, and policymakers for conceptual and statistical information that addresses the changing universe of disability, including systems change issues. *Applicable Program Regulations:* 34 CFR part 350.

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