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Part IV

Department of Education

National Institute on Disability and Rehabilitation Research; Notice

DEPARTMENT OF EDUCATION

National Institute on Disability and Rehabilitation Research

AGENCY: Office of Special Education and Rehabilitative Services, Department of Education.

ACTION: Notice of proposed priorities.

SUMMARY: The Assistant Secretary for Special Education and Rehabilitative Services proposes funding two priorities, one priority on Aging-Related Changes in Impairment for Persons Living with Physical Disabilities and a priority on Personal Assistance Services under the Rehabilitation Research and Training Center (RRTC) Program for the National Institute on Disability and Rehabilitation Research (NIDRR) for fiscal years (FY) 2002–2004. The Assistant Secretary takes this action to focus research attention on an identified national need. We intend these priorities to improve the rehabilitation services and outcomes for individuals with disabilities.

DATES: We must receive your comments on or before June 19, 2002.

ADDRESSES: Address all comments about these proposed priorities to Donna Nangle, U.S. Department of Education, 400 Maryland Avenue, SW., room 3412, Switzer Building, Washington, DC 20202–2645. If you prefer to send your comments through the Internet, use the following address: *donna.nangle@ed.gov.*

You must include the term Aging-Related Changes in Impairment for Persons Living with Physical Disabilities or Personal Assistance Services in the subject line of your electronic message.

FOR FURTHER INFORMATION CONTACT: Donna Nangle. Telephone: (202) 205–5880.

If you use a telecommunications device for the deaf (TDD), you may call the TDD number at (202) 205–4475 or via the Internet: *donna.nangle@ed.gov.*

Individuals with disabilities may obtain this document in an alternative format (*e.g.,* Braille, large print, audiotape, or computer diskette) on request to the contact person listed under **FOR FURTHER INFORMATION CONTACT.**

SUPPLEMENTARY INFORMATION:

Invitation to Comment

We invite you to submit comments regarding the proposed priorities.

We invite you to assist us in complying with the specific requirements of Executive Order 12866 and its overall requirement of reducing regulatory burden that might result from the proposed priorities. Please let us know of any further opportunities we should take to reduce potential costs or increase potential benefits while preserving the effective and efficient administration of the program.

During and after the comment period, you may inspect all public comments about the priorities in room 3412, Switzer Building, 330 C Street, SW., Washington, DC, between the hours of 8:30 a.m. and 4:00 p.m., Eastern time, Monday through Friday of each week except Federal holidays.

Assistance to Individuals With Disabilities in Reviewing the Rulemaking Record

On request, we will supply an appropriate aid, such as a reader or print magnifier, to an individual with a disability who needs assistance to review the comments or other documents in the public rulemaking record for the proposed priorities. If you want to schedule an appointment for this type of aid, please contact the person listed under **FOR FURTHER INFORMATION CONTACT.**

We will announce the final priorities in a notice in the **Federal Register**. We will determine the final priorities after considering responses to this notice and other information available to the Department. This notice does not preclude us from proposing or funding an additional priority, subject to meeting applicable rulemaking requirements.

Note: This notice does not solicit applications. In any year in which we choose to use these proposed priorities, we invite applications through a notice published in the **Federal Register**. When inviting applications we designate each priority as absolute, competitive preference, or invitational.

The proposed priorities refer to President Bush's New Freedom Initiative (NFI). The NFI can be accessed on the Internet at the following site: *http://www.whitehouse.gov/news/freedominitiative/freedominitiative.html.*

The proposed priorities also refer to NIDRR's Long-Range Plan (the Plan). The Plan can be accessed on the Internet at the following site: *http://www.ed.gov/offices/OSERS/NIDRR/Products.*

Description of the Rehabilitation Research and Training Centers (RRTC) Program

The RRTCs conduct coordinated and integrated advanced programs of research targeted toward the production of new knowledge, to improve rehabilitation methodology and service delivery systems, alleviate or stabilize disabling conditions, or promote maximum social and economic independence for persons with disabilities. RRTCs operate in collaboration with institutions of higher education or providers of rehabilitation or other appropriate services. Additional information on the RRTC program can be found at: *http://www.ed.gov/offices/OSERS/NIDRR/Programs/res_program.html#RRTC.*

General Requirements

The RRTC must:

- Carry out coordinated advanced programs of rehabilitation research;
- Provide training, including graduate, pre-service, and in-service training, to help rehabilitation personnel more effectively provide rehabilitation services to individuals with disabilities;
- Provide technical assistance to individuals with disabilities, their representatives, providers, and other interested parties;
- Disseminate informational materials to individuals with disabilities, their representatives, providers, and other interested parties;
- Serve as centers for national excellence in rehabilitation research for individuals with disabilities, their representatives, providers, and other interested parties.

Priorities

Aging-Related Changes in Impairment for Persons Living With Physical Disabilities

Background:

In recent years, advances in medical science, technology, rehabilitation, public health, and consumer education have resulted in increased life expectancies for individuals with physical disabilities. Individuals with physical disabilities face challenges, not only with the physical, mental and social manifestations of ''normal'' aging, but also the cumulative effects of chronic, disability-specific functional impairments. The impact of these new, physical, functional, and psychosocial changes are often unanticipated and are variable, depending on a myriad of factors including, but not limited to, disability severity and age of onset, presence of secondary health conditions, access to community-based supports, caregiver support and burden, and access to routine health care. (Aging with Disability, RRTC on Aging with a Disability, *http://www.jik.com/awdrtcawd.html).*

The 1997 Census data estimate that 33.0 million individuals, 12.3 percent of

the population had a severe disability. Individuals 15 years of age and over were defined as having a severe disability if they: (1) Used a wheelchair, cane, crutches, or walker; (2) had other mental or emotional conditions that seriously interfered with everyday activities; (3) received federal benefits based on their inability to work; (4) had Alzheimer's disease, mental retardation, or a developmental disability; or (5) were unable to perform (without assistance) one or more activities of daily living, instrumental activities of daily living, or functional activities such as seeing, hearing, speaking, lifting, walking, or grasping small objects (U.S. Census Bureau, Census 1996 Survey of Income and Program Participation: Aug.–Nov. 1997, pg. 2).

For those 21 million individuals who reported having a disability in a single domain, those 15 years of age and older confirmed having a disability in the physical domain. This represents a substantially higher proportion than those declaring disability in the communication or mental domains (U.S. Census Bureau, Census 1996 Survey of Income and Program Participation: Aug.–Nov. 1997, Table 2, pg. 13).

It is recognized that there are numerous widely accepted definitions for physical disability used in the disability and rehabilitation research literature. For the purposes of this priority, Verbrugge's definition of the physical class of disability will be used. As stated, ''physical disability refers to difficulty in performing basic actions required for daily living, such as mobility, purposeful movement, balance, and strength,'' (*Verbrugge L., Disability,* Rheumatic Disease Clinics of North America, Nov. 1990; 16(4)). Physical disabilities are often referred to in the context of being able to perform self-care activities or activities required for community living (Ostir G.V., *Disability in Older Adults 1: Prevalence, Causes and Consequences,* Behavioral Medicine, Winter 1999; 24(4): 147–56, pg.2). Some examples of physical disabilities include, but are not limited to: Spinal Cord Injury (SCI); Cerebral Palsy (CP); Post-Polio Syndrome (PPS); Muscular Dystrophy (MD); and Multiple Sclerosis (MS). Many individuals with these long-term conditions describe the onset of increased pain, spasticity, joint stiffness and generalized fatigue, decreased muscle strength, reduced stamina and endurance (*Aging, Well-Being and Cerebral Palsy,* The Roeher Institute Final Report, submitted October 1996, *http://www.ofcp.on.ca/aging.html;* Gueze R., et al., *Clinical and research diagnostic criteria for developmental coordination disorder: a review and discussion,* Human Movement Science 2001 Mar; 20(1–2): 7–47; Siddall P.J. & Loeser J.D., *Pain following spinal cord injury,* Spinal Cord, 2001; 39: 63–73). For example, studies show that persons aging with SCI routinely report increased fatigue and pain *(Functional Change Fact Sheet 3, http://www.agingwithsci.org).* Individuals diagnosed with PPS encounter new, progressive muscle weakness, increases in pain, diminished energy levels up to 15 years after their original illness *(Post Polio Syndrome: Identifying Best Practices in Diagnosis and Care, http://www.modimes.org).*

Classic studies on aging, such as, the Baltimore Longitudinal Study of Aging have provided a plethora of baseline data from which gerontologists and geriatric professionals have documented the physiological, psychological, and social aspects of the normal aging process. As a result of more recent studies conducted in the disability and rehabilitation arena, findings are emerging that begin to support and frame: (1) documentation and characterization of the atypical aging patterns noted in many individuals with physical disabilities and (2) systematic identification and development of strategies to measure and assess aging related changes and increases in severity of impairment.

Measurement of changes in impairment associated with aging with a disability is as complex and dynamic as the myriad of medical, socio-demographic, and psychosocial factors that influence the aging process. Gerontology, sociology and allied health literature suggest that, across disability groups, examination of the variability and interrelationship of five factors are critical to successfully measuring and characterizing aging-related changes and the overarching impact these changes may have on activity limitation and participation across major life domains. These factors are: (1) The era in which the individual is diagnosed (period of onset); (2) the chronological age at which disability occurs (age of onset) (3) duration of disability; (4) initial severity; and (5) the presence or onset of secondary conditions.

Study across diagnostic groups has been especially difficult because of the wide array of secondary conditions and confounding complications resulting from routine aging and associated with the primary condition causing disability. Public health experts agree that secondary conditions constitute a significant and shared health risk for individuals aging with physical disabilities. Individuals with polio and rheumatoid arthritis report experiencing osteoarthritis, diabetes, heart disease, high blood pressure, and asthma. (Campbell M.L., *et al., Secondary health conditions among middle-aged individuals with chronic physical disabilities: implications for unmet needs for services,* Assistive Technology; 1999; 11(2): 105–122). Individuals with SCI and other chronic physical disabilities also report health problems such as hypertension, high cholesterol, cardiopulmonary disorders, obesity, osteoporosis, bone fractures, and pressure ulcers, which are all considered to be of especially high incidence in individuals with chronic physical disability (Garland D.E., *et al., Bone Loss with Aging and the Impact of SCI,* Topics in Spinal Cord Rehabilitation, 6: 3, 61–69; Kraft G.H., *Multiple Sclerosis: A Rehabilitative Approach, http://depts.washington.edu/rehab/ms/narrative.shtml).*

In general, inviduals aging with a physical disability are more likely than their non-disabled peers to experience declines in health status, increases in severity of impairment, reduction in level of activity, and reduced participation in major life activities. These aging-related changes can lead to decreased functional independence and diminished quality of life for some individuals while others may experience relative stability in function as they age with their physical disability. (Ostir G.V., *Disability in Older Adults 1: Prevalence, Causes and Consequences,* Behavioral Medicine, Winter 1999; 24(4): 147–56; Carlson J.E., *Disability in Older Adults 2: Physical Activity as Prevention,* Behavioral Medicine, Winter 1999; 24 (4): 157–68; Guttman C., *Older Americans 2000: New data system that tracks health and well-being finds successes and disparities,* Geriatrics, Oct 2000; 55(10): 63–6,69).

Further, as compared to the non-disabled population, aging-related changes have a greater impact on individuals with physical disabilities who are already less likely to work, attend college, access and utilize community-based services, and participate in recreation and leisure time activities. These same individuals are often more likely to experience clinical depression, encounter social isolation and substance abuse problems (Maloni H.W., *Pain in multiple sclerosis: an overview of its nature and management,* Journal of Neuroscience Nursing, 2000; June; 32(3): 139–44, 152; Kaplan G.A., *et al., Natural history of leisure-time physical activity and its correlates: associations with mortality from all causes and cardiovascular disease over 28 years,* American Journal

of Epidemiology, 1996; 144: 793–7; Mendes de Leon, *et al., Self-efficacy, physical decline, and change in functioning in community-living elders: a prospective study,* Journal of Gerontology and Social Science, 1996; 51: 183–90). Through the implementation of the NFI and the Plan, NIDRR seeks to address the issues of aging with a physical disability, with particular attention on preventing or minimizing changes in impairment or both that impact activity and participation in major life domains.

Focusing on both individual and systemic factors that impact function, activity and participation, the NFI emphasizes the importance of access to assistive and universally-designed technologies, employer and workplace supports, and promoting full access to community-based care. The Plan, which emphasizes the need for consumer knowledge and information, new techniques, and technologies and advancements in the overall body of scientific knowledge, calls for research to improve individual outcomes in employment, health and function, technology for access and function, and independent living and community integration. Clearly, the challenges and opportunities for research on the unique and varied issues of aging across disability groups are reflected throughout the elements of the NFI and the Plan.

Priority 1

The Assistant Secretary proposes to establish a Rehabilitation Research and Training Center on Aging-Related Changes in Impairment for Persons Living with Physical Disabilities. The purpose of this absolute priority is to generate new knowledge regarding the characteristics, prevalence, and distribution of these changes, their interrelationships with lifestyle and environmental factors, and their consequences on health, activity, and participation across the life span. The priority seeks to improve rehabilitation outcomes by encouraging innovative interventions aimed at preventing or minimizing the impact of aging-related changes on the well-being and productivity of persons with physical disabilities. The RRTC is required to conduct significant and substantial cross-disability research and is encouraged to collaborate with one or more institutions, for the purposes of ensuring inclusion of multidisciplinary expertise across disability groups, and sufficient sample size and methodological rigor to generate robust findings.

The RRTC must:

(1) Clarify definitions and critically review and analyze strategies to measure aging-related changes in physical, psychological, and sensory impairment within and across at least two physical disabilities such as, but not limited to, SCI, CP, PPS, MD, and MS;

(2) Using the disabilities selected, document aging-related changes and examine variations in terms of prevalence, magnitude of change, timing of onset (age and duration of disability), onset severity and socio-demographic distribution within, and between study groups;

(3) Develop a conceptual model, grounded in an appropriate theoretical framework, of aging-related changes in impairment that: (a) Predicts determinants of increases or stability in severity of impairment such as age, disability, lifestyle, or environmental factors; (b) quantifies the interrelationships between stability and increases in impairment and the occurrence of secondary health conditions; and (c) evaluates the consequences of changes in impairment on activity and participation across major life domains;

(4) Using the model (see (3)) as a framework, identify or develop and evaluate rehabilitation techniques or interventions, or both, to mitigate the direct consequences of changes in impairment on health, activity limitations, and participation in employment, family life, independent living, community integration, and leisure and recreational activities; and

(5) Develop, implement, and evaluate a comprehensive plan to train policymakers, researchers, practitioners, service providers and advocates in rehabilitation and disability-related fields, and consumers and family members about aging-related changes in impairment, and the consequences for health, participation and quality of life of individuals with physical disabilities.

In carrying out the purposes of the priority, the RRTC shall:

- Develop and implement during the first year of the grant, and in consultation with the National Center on Dissemination of Disability Research (NCDDR), a comprehensive plan that promotes broad dissemination to both consumer and professional audiences;
- Involve consumers and family members as appropriate in all stages of research and related activities;
- Address the unique needs of individuals aging with physical disabilities who are members of groups that have traditionally been underrepresented, and demonstrate use of culturally appropriate methods of data collection, measurement and dissemination;
- Collaborate on projects, as appropriate, with NIDRR-funded RRTCs, RERCs, and Model Systems, and other public and private agencies and institutions;
- In the fourth year of the project, conduct a state-of-the-science national conference to disseminate and discuss the results of the research with researchers, policymakers, consumers, family members, and other stakeholders; and
- Demonstrate appropriate multidisciplinary linkages to Geriatrics, Gerontology and Rehabilitation.

Personal Assistance Services

Background

Personal Assistance Services (PAS) ''means a range of services, provided by one or more persons, designed to assist an individual with a disability to perform daily living activities on or off the job that the individual would typically perform if the individual did not have a disability. The services shall be designed to increase the individual's control in life and ability to perform everyday activities on or off the job.'' (34 CFR 385.4(b)). In practice, PAS may be provided to a range of populations, with a variety of disabilities, through a number of delivery models with varying types of services, and using a variety of funding mechanisms. NIDRR's Long-Range Plan (the Plan) sets a goal in which PAS is based upon a support model, with the consumer having primary control.

In both the New Freedom Initiative (NFI) and in his Executive Order (E.O.) 13207 on Community-Based Alternatives for Individuals with Disabilities derived from the Supreme Court's Olmstead decision, the President states a clear intent ''to help ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life'' *(http://www.whitehouse.gov/news/releases/2001/06/20010619.html).*

The combination of policies, protections, and mandates underscores the appropriateness of a continued strong research focus on factors associated with PAS at home, in the community, and at the worksite. The goal of these efforts is to maximize the range of options available to individuals with disabilities to ensure their full integration into and participation in society.

PAS includes assistance with activities of daily living (ADLs), such as eating, bathing, dressing, or toileting, or instrumental activities of daily living (IADLs), such as preparing meals, managing money, or shopping. ''Work-related PAS might include filing, retrieving work materials that are out of reach, or providing travel assistance for an employee with a mobility impairment; helping an employee with a cognitive disability with planning or decision making; reading handwritten mail to an employee with a visual impairment; or ensuring that a sign language interpreter is present during staff meetings to accommodate an employee with a hearing impairment'' (President's Committee on Employment of People with Disabilities, *Personal Assistance Services in the Workplace,* 2000, *http://www.odc.state.or.us/tadoc/ada69.htm).*

In an analysis of data from the National Health Interview Survey on Disability (NHIS–D), 1994–95, LaPlante, Harrington, and Kang found that almost 13.2 million individuals in the U.S. needed or received an average of 31.4 hours per week of help with ADLs or IADLs, for a total of 22 billion hours of care annually. Most of that care was from unpaid caregivers (LaPlante M., Harrington C., and Kang T., *Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults Living at Home,* Health Services Research, 2002, publication pending). In other work based upon the same data source, the authors found that a substantial number of individuals reported that they needed more help than they received, with lower incomes being a key factor in whether or not the individual needed additional PAS (Harrington C., LaPlante M. and Kang T., *Estimating the Amount and Cost of the Unmet Need for Personal Assistance Services at Home,* Disability Statistics Center, draft 2000). Also, data from the NHIS–D indicate that more than 500,000 people would need help with the work-related tasks mentioned earlier in order to work—of that number, 176,000 are working, with 44,000 not being accommodated (e-mail communication to NIDDR Staff from Kay, S., Jan. 31, 2002).

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. For example, persons age 65 and older have a greater need for PAS than do persons of working age, 21 to 64 (LaPlante, Harrington & Kang, 2000; McNeil J., *Americans with Disabilities: 1997,* U.S. Census Bureau, 2001). The effect of such a trend can be seen in the unmet needs for PAS and, for some, the need to rely upon a barely adequate patchwork of services. The specific nature of disability, whether physical, cognitive, or psychiatric, must also be evaluated in terms of significance to the availability of PAS that is appropriate to the individual. The Olmstead decision, NFI, and other policies and initiatives create what may be a fertile opportunity for expansion of PAS that reflects the independent living perspective.

Availability of, and payment for, worksite PAS requires models that allow greater freedom for individuals with disabilities to remain in, or re-enter, the workforce. Sometimes, ''in the workplace, PAS is provided as a reasonable accommodation to enable an employee to perform the functions of a job. The employer's responsibility for providing reasonable accommodations begins when the employee reaches the job site and concludes when the work day ends'' (President's Committee on Employment of People with Disabilities, 2000). Given the generally lower earnings of people with severe disabilities as compared to those without disabilities (McNeil, 2001), a substantial barrier may remain for individuals with lower earnings in particular. Workers with disabilities who may lack access to public programs or adequate health insurance may be unable to afford PAS at home and in the community.

A recent report of the National Blue Ribbon Panel on PAS notes that ''for many individuals with disabilities, absence of assistance with * * * non-medical, day-to-day activities * * * can affect the musculoskeletal, circulatory, respiratory, and skin systems * * * and can result in greater levels of disability and even greater need for health and support services'' (Dautel and Frieden, *Consumer Choice and Control: Personal Attendant Services and Supports in America, http://www.ilru.org/pas/BRPPAS.htm,* 1999). Living in the community with severe disability can require negotiation of a complex variety of programs and services to find appropriate PAS. In addition, depending upon geographic location, availability of family and other informal supports, respite care, and of course financial assets, adequate PAS may not be assured. As Harrington and LeBlanc report, the availability of home- and community-based services under Medicaid varies widely depending upon location (Harrington C. and LeBlanc A.J., Medicaid Home and Community-Based Services, Disability Statistics Report, 16, 2001). McNeil finds that people with severe disabilities are less likely than those without disabilities to be a householder and are more likely to live as an unrelated individual. Analysis of model policies to provide formal and informal assistance must be sensitive to the range of sociodemographic variables.

The availability of PAS is a complex issue involving many factors that affect community living and participation in employment activities. Individuals with disabilities and personal care assistants alike have reported numerous PAS workforce gaps, which negatively impact the provision of PAS services to individuals with disabilities. Recruiting potential PAS workers is hampered because of low pay, poor benefits, and lack of opportunities for professional training, development, networking, and career advancement (*Focus on the Frontline: Perceptions of Workforce Issues Among Direct Support Workers and Their Supervisors,* National Center on Outcomes Resources, *http://www.qualitymall.org/products/FMPro?-DB=qmproducts&-Lay=products&-format=product_1.html&-Error=error.html&-RecID=34051&hits=17&-Edit,* 2001). PAS providers also report difficulties measuring success, another factor that contributes to worker burnout (Cockerill R. and Durham N., *Attendant Care and Its Role in Independent Living, as Developed in Transitional Living Centres,* New England Journal of Human Services, 1992). Retaining existing PAS providers is difficult for the same reasons; as a result, morale is low and turnover rates are high.

Mending these gaps is necessary to ensure successful independent and community living for individuals with disabilities. Bob Kafka of American Disabled for Attendant Programs Today notes that ''whatever our solution it is clear that outreach for attendants will be essential if choice and control are to have any real meaning'' (Kafka, B., *Empowering Service Delivery: Evolving Home Health for the 21st Century, http://www.libertyresources.org/mc/ca-26.html,* 1998). The importance of training for PAS providers is clear, with some consumer groups noting that training should encompass philosophical as well as technical matters. Kafka writes, for example, that ''training should not focus so much on medical needs of the individual but rather on independent living principles, disability rights, body mechanics.* * *'' NIDRR-funded grantees and others have addressed some of these issues in conjunction with specific geographic or target populations and determined that what is needed is

an effort that is geographically diverse, covers a range of individuals with disabilities, and addresses issues raised by new policy initiatives.

Although the quality of PAS is impacted by training issues, policies, low wages, and other complexities, the extent of the PAS worker's knowledge about the needs of consumers is a major concern. For example, knowledge of assistive technology (AT) is critical to enabling individuals with disabilities to live as independently as possible. Therefore, workers can be trained about the range of AT resources available to individuals with disabilities. Information can be provided about how these devices work, how to obtain them, and how to assist individuals with disabilities to use them independently, to the greatest extent practicable. As one consumer report notes, it is important to combine ''the skills of listening and networking with the knowledge of resources and technical assistance to address the needs of people with disabilities in a timely manner'' (*People with Physical Disabilities are Speaking Out About Quality and Services,* National Center on Outcomes Resources, 2001).

Another important aspect of PAS affecting the well-being and productivity of persons with significant disabilities is the relationship between formal assistance and informal, unpaid assistance from family and friends. Although formal and informal care are in principle largely complementary, estimates from the 1994 National Long-Term Care Survey quoted by R. Stone indicate that the majority of noninstitutionalized elders with disabilities (67 percent) rely solely on unpaid help from family members (Stone R., *Long-Term Care for the Elderly with Disabilities; Current Policy, Emerging Trends and Implications for the Twenty-First Century, http://www.milbank.org/0008stone/index.html,* 2000). Other studies have estimated that 60–80 percent of all personal assistance and long-term care services in the United States, regardless of age, are provided by families (Morris R., Caro F., and Hansan J., *Personal Assistance; The Future of Home Care,* The Johns Hopkins University Press, 1998).

Key questions are: (1) To what extent, and how, is informal help from family and friends being used to supplement or replace the need for paid personal assistance services to support the employment, functional independence, and community integration of working-age and older adults with disabilities; (2) how satisfied are consumers with the combination of formal and informal services they receive; and (3) how does the provision of informal services affect the amount of paid personal assistance they utilize? In tandem with other issues surrounding PAS, the balance between formal and informal services is inextricably tied to funding sources, whether public or private. Research suggests that the degree to which funding streams, especially public programs such as Medicaid, pay for formal PAS in lieu of, or to supplement, informal PAS has substantial cost implications (Harrington, LaPlante, and Kang, 2000).

Priority 2

The Assistant Secretary proposes to establish a Rehabilitation Research and Training Center on Personal Assistance Services. The purpose of this absolute priority is to support methodologically rigorous collaborative research to generate new knowledge that informs service delivery providers and policymakers regarding the need for and provision of PAS at the worksite, in the community, and in home-based settings for individuals with physical, sensory, cognitive, psychiatric, and multiple disabilities.

The activities are:

(1) Identify or develop, or both, evaluate, and disseminate best practices for PAS at the worksite to facilitate employment of individuals with disabilities who need such accommodations;

(2) Identify or develop, or both, evaluate, and disseminate best practices for PAS in community- and home-based settings to facilitate maximum integration and participation by working-age and older adults with disabilities;

(3) Conduct research on the PAS workforce and workforce development that reflects geographic diversity and addresses PAS workforce recruitment, retention, compensation and benefits; professional training, development, and networking, for PAS providers, including communication between individual, group, public and private PAS providers; and crossover issues between disability and aging providers;

(4) Identify and analyze existing model State and Federal PAS policies and programs, and develop a database to inventory the results;

(5) Evaluate and determine the impact on, and relevance to, PAS at the worksite and in the community of recent policy initiatives, such as E.O. 13207 implementing the Olmstead decision, the NFI, and other systems change activities for changes to existing State and Federal policies and programs;

(6) Conduct research on the relationship between formal and informal PAS and caregiving support, and on the role of assistive technology (AT) in complementing personal assistance to enhance the function, access, independent living, and quality of life of working-age and older adults with disabilities. In addition, identify and evaluate barriers to obtaining and using multiple sources of support; and

(7) Identify, develop, and evaluate models to eliminate barriers encountered by working-age and older adults with disabilities in accessing and utilizing both formal and informal PAS and AT to support employment, functional independence, and community integration.

In addition to proposed activities, in carrying out these priorities, the applicant must:

- Involve individuals with disabilities or their family members, or both and persons who are members of groups that have traditionally been underrepresented, as appropriate, in all stages of research and related activities;
- In the fourth year of the project, conduct a state-of-the-science national conference to disseminate and discuss the results of the research with researchers, policymakers, consumers, and other stakeholders;
- Coordinate with other entities carrying out related research or training activities; and
- Identify coordination responsibilities through consultation with the NIDRR project officer.

Applicable Program Regulations: 34 CFR part 350.

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(Catalog of Federal Domestic Assistance Number 84.133B, Rehabilitation Research and Training Center.)

Program Authority: 29 U.S.C. 762(g) and 764(b)(2).

Dated: May 15, 2002.

Robert H. Pasternack,

Assistant Secretary for Special Education and Rehabilitative Services.

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