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Part III

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 funding priorities for fiscal years (FYs) 2001–2003 for two Disability and Rehabilitation Research Projects.

SUMMARY: We propose funding priorities for two Disability and Rehabilitation Research Projects and Centers Program (DRRP) one on Assistive Technology Outcomes and Impacts and the other on Assistive Technology Research Projects for Individuals with Cognitive Disabilities under the National Institute on Disability and Rehabilitation Research (NIDRR) for FY 2001–2003. We may use these priorities for competitions in FY 2001 and later years. We take this action to focus research attention on areas of 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 May 7, 2001.

ADDRESSES: All comments concerning these proposed priorities should be addressed to Donna Nangle, U.S. Department of Education, 400 Maryland Avenue, SW., room 3414, Switzer Building, Washington, DC 20202–2645. Comments may also be sent through the Internet: donna_nangle@ed.gov

FOR FURTHER INFORMATION CONTACT: Donna Nangle. Telephone: (202) 205–5880. Individuals who use a telecommunications device for the deaf (TDD) may call the TDD number at (202) 205–4475.

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 in the preceding paragraph.

SUPPLEMENTARY INFORMATION:**Invitation To Comment**

We invite you to submit comments regarding these 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 these 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 these priorities in Room 3414, Switzer Building, 330 C Street SW., Washington, DC, between the hours of 8:00 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 these proposed priorities. If you want to schedule an appointment for this type of aid, you may call (202) 205–8113 or (202) 260–9895. If you use a TDD, you may call the Federal Information Relay Service at 1–800–877–8339.

National Education Goals

These proposed priorities will address the National Education Goal that every adult American will be literate and will possess the knowledge and skills necessary to compete in a global economy and exercise the rights and responsibilities of citizenship.

The authority for the program to establish research priorities by reserving funds to support particular research activities is contained in sections 202(g) and 204 of the Rehabilitation Act of 1973, as amended (29 U.S.C. 762(g) and 764(b)(4)). Regulations governing this program are found in 34 CFR part 350.

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 additional priorities, 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 NIDRR's Long-Range Plan that can be accessed on the World Wide Web at: (<http://www.ed.gov/offices/OSERS/NIDRR/#LRP>).

Disability and Rehabilitation Research Projects and Centers Program

The purpose of the program is to plan and conduct research, demonstration

projects, training, and related activities to:

(a) Develop methods, procedures, and rehabilitation technology that maximizes the full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities; and

(b) Improve the effectiveness of services authorized under the Act.

Proposed Priority 1: Assistive Technology Outcomes and Impacts*Background*

One of the greatest challenges facing health care systems, social services providers and policymakers is to ensure that scarce resources are used efficiently. To a large extent, this challenge explains the growing interest in outcomes research and evidence-based medicine. Particular interest in outcomes of assistive technology (AT) is related to the amount of dollars spent on developing and manufacturing AT, AT service delivery and to the need to improve the functional independence and well-being of persons with disabilities of all ages. Yet, assessment of the impact of technology on function and other productivity and quality of life outcomes lags behind outcomes measurement in other areas of rehabilitation.

There are several factors that promote concern about the paucity of outcomes research in AT including the: (a) Ability to demonstrate efficacy of new devices; (b) need to examine effectiveness of devices over time; and (c) need to chart future research and development to improve devices (Fuhrer, M. J., "Assistive technology outcomes research: challenges met and yet unmet," *American Journal of Physical Medicine and Rehabilitation*, 2001, In press). Outcomes research and analysis is also needed to guide decisionmaking across multiple levels of policy and program development, including: (a) Decisions on a societal level regarding types of public programs and services to fund; (b) decisions on a programmatic level regarding what services to continue, enhance, modify or eliminate; (c) decisions on an individual level regarding AT recommendations and interventions; and (d) decisions on a research level regarding the comparative effectiveness of individual devices and the impact on future designs (Smith, R., "Measuring the outcomes of assistive technology: challenge and innovation", *Assistive Technology*, Vol. 8, No. 2, pgs. 71–81, 1996).

In the face of a growing interest in outcomes, the inconsistent use of

terminology contributes to the confusion that exists in the application of a generally accepted outcomes approach. In the field of rehabilitation, outcomes measurement has focused on creating outcomes management systems and measuring and communicating outcomes. Rehabilitation has led the health care field in its emphasis on changes in function as an outcomes measure. Still, even in rehabilitation, outcomes measurement systems have typically focused on process variables, *i.e.*, the outputs of products and services, and not on gains to the individual or society in either the short or long term. Wilkerson posits that this emphasis on process will change because of three factors: (a) The pressure to cut costs; (b) growth of consumerism leading to increased input from users and increased focus on the needs of the end user; and (c) concerns about quality in relation to costs (Wilkerson, D., "Outcomes and accreditation—The paradigm is shifting toward outcome," *Rehab Management*, August/September, pgs. 112–115, 1997).

Outcomes research is defined in different ways across rehabilitation and health services research as well as in the social services field. The Foundation for Health Services Research (Foundation for Health Services Research, *Health Outcomes Research: A Primer*, Washington, DC, 1994) characterized outcomes research as research focused on the "end results of medical care—the effect of the health care process on the health and well-being of patients and populations." The Institute of Medicine (IOM) (Feasley, J.C., ed., *Health Outcomes for Older People: Questions for the Coming Decade*, Washington, DC: National Academy Press, 1996) expanded this definition to include "the clinical signs and symptoms, well-being or mental and emotional functioning; physical, cognitive, and social functioning; satisfaction with care; health-related quality of life, and costs and appropriate use of resources." Outcomes research has also been defined as research designed to discover the sustained impact of rehabilitative strategies and treatments in the everyday lives of persons with disabilities. "Outcomes research attempts to build a bridge between interventions and long-term improvements in the lives of persons served as they reenter the community" (Johnston, M., et al., "Outcomes research in medical rehabilitation—foundations from the past and directions for the future," *Assessing Medical Rehabilitation Practices: The Promise of Outcomes Research*, Marcus

J. Fuhrer, ed., pgs. 1–42, 1997). Regardless of how it is defined, outcomes research is part of the larger framework of program evaluation (Fuhrer, op cit., 1997), and includes both outcomes analysis and outcomes measurement also known as performance measurement (Jennings, B.M. and Stagers, N., The language of outcomes, *Journal of Rehabilitation Outcomes Measurement*, Vol. 3, No.1, pgs. 59–64, 1999).

Rehabilitation outcomes are changes produced by rehabilitation services in the lives of service recipients and their environments. Outcome indicators are measures of the amount and frequency of those occurrences, and include service quality. Within this perspective, some analysts use the word "impacts" to distinguish between longterm outcomes or end results that occur on a societal versus an individual level. Still others use the term "impact" more strictly to refer to estimates of the extent to which the program actually "caused" particular outcomes (Hatry, H. et al., *Customer Surveys for Agency Managers: What Managers Need to Know*, Washington, DC: Urban Institute, 1998). Deconstructing these various definitions and types of outcomes and impacts requires recognition of complexity on many levels.

Although AT has grown as a discipline and as an industry over the past two decades, there has not been a corresponding maturity in developing or assessing the outcomes or impacts of AT upon individuals with disabilities. AT devices and services outcomes also may be difficult to define because of the ways AT is used. For example, AT is used to increase participation in the environment, enhance normative social roles, promote and sustain employment, and facilitate activities of daily living. Some devices, such as computers, increase access to information and support life long learning. AT devices vary significantly from highly complex and sophisticated computer-operated systems to low tech approaches that can be easily purchased or built. Complicating the issue even further are the individual characteristics of the AT user and the varied environments in which users live, work, and learn.

Approximately one-third of AT devices will be abandoned by the user (Phillips, B. and Zhao, H. "Predictors of assistive technology abandonment", *Assistive Technology*, Vol. 5, pgs. 36–45, 1995). There are many reasons why individuals with disabilities choose to accept or reject AT devices. Since public funds provide a major source for purchasing AT devices and services, useful and accurate measures of

outcomes and impacts is critical for accountability and to avoid wasteful outcomes. Is abandonment a negative or could it be a positive outcome? Abandonment has been viewed as the end result of fragmented service provision, poor assessment techniques, lack of consumer choice in device selection, inattention to device use across environments, inadequate training, costly repairs, need to upgrade and obsolete or inappropriate technology. However, abandonment may be a natural phenomenon related to improved physical or cognitive function, the result of a technology upgrade or because different technology is a better fit between the end-user and the environment.

There are other reasons to account for the lack of momentum in measurement development and outcomes and impact research on AT. Most of the endorsements of a particular device or service are based on anecdotal information (Fuhrer, 1999) rather than data generated from research. Frank DeRuyter ("Evaluating outcomes in assistive technology: do we understand the commitment," *Assistive Technology*, Vol. 7, No. 1, pgs. 3–16, 1995), observed that historically, AT was considered a remedy to impairment or dysfunction, and the urgency of consumer need was of greater importance than relying upon data to document the efficacy of a particular device. In addition, quality was perceived as too abstract and difficult to measure and define. Vendors and practitioners may feel threatened by potential findings and accountability demands, which may also have contributed to the lack of outcomes studies (DeRuyter, op. cit, 1995).

While the AT arena is complex and broad, several outcomes studies have focused on a discrete segment of the entire system. Smith says that there are essentially two domains of outcome measurement: the performance of an individual using assistive technology and the cost of achieving the level of performance (Smith, R.O., "Accountability in assistive technology interventions: measuring outcomes," *Volume I—RESNA Resource Guide of Assistive Technology Outcomes: Measurement Tools*, pgs. 15–43, 1998). Minkel proposed that the primary measure to determine the value of the assistive technology is the basic formula of outcomes divided by cost (Minkel, J., "Assistive technology and outcomes measurement: Where do we begin?" *Technology and Disability*, July, pgs. 285–288, 1996). There are others within the AT community who operate under the assumption that improvements and innovation in technology will

“naturally” lead to successful use and implementation, and therefore do not need to be evaluated. From this perspective, technological solutions have been viewed as a panacea without the benefit of data to support prevailing assumptions (De Ruyter, F., “Concepts and rationale for accountability in assistive technology,” *Volume I—RESNA Resource Guide of Assistive Technology Outcomes: Measurement Tools*, pgs. 2–15, 1998).

At a minimum, the process of evaluating AT outcomes must measure and establish a baseline of what works, identify how well and for whom it works, and at what level of economy and efficiency. This process will necessitate taking information from several performance monitoring dimensions (De Ruyter, op. cit., 1998). In approaching the challenges of AT outcomes measurement, it is important to identify if the outcomes relate to the AT product or service, the user, or to the environment in which the technology is being used. While not standardized or widely endorsed, a variety of measurement techniques and instruments are currently utilized. These measurement tools tend to be specific to a given practice area or limited to a functional domain, (*Volume I: RESNA—Resource Guide for Assistive Technology Outcomes: Measurement Tools*, 1998).

To proceed with assessing AT outcomes and impacts, the following questions need to be addressed. First, what are the key gaps and weaknesses in our knowledge of AT use and its impacts? Are the key research questions related to a particular intervention at a particular point in time? How do device modifications and upgrades change the intervention? How do characteristics of the population including severity of impairment, duration of disability, presence of co-morbidities, aging and other sociodemographic factors influence technology utilization and bias outcomes study? What is the role of environmental, economic, awareness and training barriers in AT use and outcomes? These different levels of outcomes can look at impacts and effects of technology at one point in time, more typically a clinical or functional outcome, or can be examined in terms of long-term impacts on individual quality of life, productivity and social participation. As one researcher expressed it, in addition to longitudinal studies, “the research agenda must consider lifelong use of assistive technology, documenting effectiveness of that technology as an intervention, identifying stages for reconsideration of its use, and defining

environmental and social considerations” (Turk, M. A., “Early development-related condition,” *Assessing Medical Rehabilitation Practices—The Promise of Outcomes Research*, Marcus J. Fuhrer, ed., pgs. 367–392, 1997).

Innovations in AT will continue to evolve and many AT users, as they have in the recent past, will experience increases in independence, function, and general well being. Concurrently, the gap between the promise of technology and the ability of individuals and funding sources to afford them will continue to widen. This will result in a greater need for knowledge about the cost-effectiveness and efficiency of particular devices and services (Fuhrer, M.J., “Assistive technology outcomes research: challenges met and yet unmet,” *American Journal of Physical Medicine and Rehabilitation*, 2001, In press).

Proposed Priority 1: Assistive Technology Outcomes and Impacts

We propose to establish multiple research projects on assistive technology (AT) outcomes and impacts to determine the efficacy and utility of AT interventions and the implications for abandonment of AT devices. In carrying out these purposes, the projects must:

- (a) Assess the current status of AT outcomes and impacts measurement systems and approaches, identifying measurement methodologies, characteristics of key instruments including utility to AT field, and critical gaps in measurement;
- (b) Based upon the findings of paragraph (a), evaluate efficacy of existing measurement instruments or develop and evaluate new outcomes and impacts measurement methodologies to meet the needs of AT stakeholders; and
- (c) Investigate and analyze the complexity of factors contributing to the abandonment of AT, including age-related changes, and identify how these factors are incorporated into outcomes and impacts measurement instruments.

In addition to activities proposed by the applicants to carry out these purposes, each project must:

- Develop and disseminate to AT stakeholders and other interested and relevant audiences, as determined by NIDRR, materials on AT outcomes studies and impacts analyses and, periodic updates on the project’s milestones, products and results; and
- Collaborate with relevant NIDRR-sponsored projects, such as the AT/IT Consumer Survey (University of Michigan), the RESNA Technical Assistance projects, and the RRTC on Medical Rehabilitation Outcomes, as

identified through consultation with the NIDRR Project Officer.

Proposed Priority 2: Assistive Technology Research Projects for Individuals With Cognitive Disabilities

Background

Technology and assistive devices have commonly been used to assist persons with mobility, communication and sensory difficulties. Because of the positive impact that technology has played in the lives of these individuals, there is now a strong push toward the development of such devices for people with cognitive disabilities. The Assistive Technology Act of 1998 defines an assistive technology device to be any item, piece of equipment or product system whether acquired commercially off the shelf, modified or customized that is used to increase, maintain or improve functional capabilities of individuals with disabilities. Rapid advances in technology provide great potential for development of new devices or adaptation of available devices to assist individuals with cognitive disabilities to develop and maintain skills.

Technology professionals, such as computer scientists and rehabilitation engineers, have limited experience applying assistive technology solutions to users with cognitive disabilities. Nor do they yet understand the mapping between specific needs and equally specific design solutions. Most people with cognitive disabilities have a range of learning and processing capabilities. Wide variations in cognitive functioning make it difficult to develop generic solutions appropriate for all individuals. Functional capabilities associated with these disabilities may include wide ranges of ability in memory, reasoning, and language comprehension. Cognitive functioning also includes perception, problem-solving, conceptualizing, reading, thinking and sequencing (Electronic and Information Technology Access Advisory Committee, “EITAAC Report, May 13, 1999,” A Report to the Architectural and Transportation Barriers Compliance Board). Common strategies to improve functioning in activities of daily living across various cognitive disabilities need to be identified, as do, issues regarding information processing that may be unique to each of these groups.

Persons with cognitive disabilities often have difficulty in carrying out Instrumental Activities of Daily Living (IADLs) because of problems with time management and information retrieval. Researchers are experimenting with the use of electronic personal computers to

compensate for memory problems. Other researchers are examining methods of matching individual cognitive problems with compensatory strategies provided by a variety of commercially available portable electronic devices. In traumatic brain injury treatment, researchers are investigating the use of virtual reality technology to test visual acuity and reaction times to stimulus. Research is also being conducted on the use of text-based messages to enhance communication.

Technology is often viewed as facilitating employment of persons with disabilities. However, inaccessible technology can be a barrier to all persons with disabilities. This is particularly true for persons with cognitive impairments who may have difficulty using telephones, computers, and other equipment that are staples of most work environments. Developers and manufacturers of assistive technology often do not consider issues of cognitive access and flexibility when designing their products.

While the congruence between the promise of assistive technology and the needs of many people attempting to achieve community integration is obvious, little has been written about the manner in which technology affects community adaptation or the service needs of individuals with cognitive disabilities in community settings. While specific manifestations of assistive technology have identifiable benefits, the central question needs to be empirically addressed—how can assistive technologies contribute to community integration and in what manner can the linkage be facilitated? The state of knowledge about the use of assistive technology for persons with cognitive disabilities, as well as the outcomes of that use or lack of use and the cost-effectiveness in achieving community integration is limited. There are only a few large assessments of the technology needs of persons with cognitive disabilities and results are ambiguous because of difficulties in identifying persons with low incidence conditions and specific technology needs within the study population (Lakin, C. et al., NIDRR Long-Range Plan Commissioned Paper on Community Integration, 1996).

In order to take advantage of any potential that technological advances may have, it is important to define what makes a device easier or more difficult for a person with a cognitive disability to use. Products that are simpler and

require fewer cognitive skills are easier to operate for everyone (Vanderheiden, G., 1992, "A brief look at technology and mental retardation in the 21st century," in *Mental Retardation in the Year 2000*, Louis Rowitz, ed., New York: Springer-Verlag). "Design guidelines" must then be communicated to the manufacturers of consumer products and business information systems. Instructions for training on the use and maintenance of the device also need to be part of this design process. It is important for designers to be aware of the real world tasks with which the user has difficulty; hence, research needs to include persons with cognitive disabilities at the front end of all technology development. End product affordability is important not only in meeting consumer needs, but also in creating the market demand that will encourage manufacturers to enter production.

The NIDRR Long-Range Plan discusses three objectives in developing technology to meet the needs of people with limitations in cognitive functioning: To assure that new technologies are accessible and do not exacerbate exclusion from mainstream activities; to assist people with cognitive limitations in the performance of daily activities; and to develop technologies that can enhance or restore some cognitive functions (NIDRR, Long-Range Plan: 1999–2003, pg. 57).

The University of Colorado recently accepted a gift of \$250 million. The endowment will fund advanced research and development of innovative technologies to enhance the lives of people with cognitive disabilities. The endowment, to be paid over five years, will be used to establish the Coleman Institute for Cognitive Disabilities located at the University of Colorado. Applicants for this project should provide information on proposed coordination with the Coleman Institute.

Proposed Priority 2: Assistive Technology Research Projects for Individuals With Cognitive Disabilities

We propose to establish multiple research projects on technology access for persons with cognitive disabilities leading to practical and affordable solutions to identified community and workplace needs of this population. The projects must:

- (a) Conduct an assessment of state-of-the-art technology applications for persons with cognitive disabilities;
- (b) Based on the assessment results of paragraph (a), identify technology gaps

and needs for persons with cognitive disabilities and make recommendations for new technology and modifications to existing technology; (c) Identify features that may be incorporated into existing, commercially available technology that could benefit persons with cognitive disabilities; and

(d) Develop and explore strategies for strengthening partnerships with developers and manufacturers of devices in order to facilitate the development of new technologies and applications to incorporate cognitive access.

In addition to the activities proposed by the applicants to carry out these purposes, the projects must:

- Coordinate with the appropriate Federal agencies and privately-funded projects, such as the University of Colorado's Coleman Institute for Cognitive Disabilities, that are relevant to the applicants proposed activities as identified through consultation with the NIDRR project officer; and

- Involve individuals with cognitive disabilities in all aspects of the project.

Applicable program regulations: 34 CFR part 350.

Program Authority: 29 U.S.C. 762(g) and 764(b)(4).

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Dated: April 2, 2001.

Andrew J. Pepin,

Executive Administrator for Special Education and Rehabilitative Services.

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