

NIDRR Projects

Research in the New Millennium

Integration at Home: Strengthening Family Relationships of Adults with Disabilities, University of Illinois at Chicago (H133G020146)

led by Carol J. Gill, PhD. Richard E. Wilson II, EdD, Project Officer.

Abstract: This study investigates the family relationship issues of adults with physical or mobility disabilities and adults with chronic fatigue syndrome. Phase I involves focus group interviews with adults with disabilities for an open exploration of family relationship issues. Phase II involves in-depth case studies of families experiencing disability who exemplify positive family integration. Phase III involves a randomized control group study to test the impact of a family "intervention" based on the social model of disability.



University of Illinois at Chicago Mental Health Services Research Program Medication Adherence Program Study (UIC-MAPS),

University of Illinois at Chicago

(H133G010093) led by Lisa A. Razzano, PhD.

David W. Keer, Project Officer.

Abstract: This project examines the effects of a multifaceted curriculum designed to improve adherence to medication and treatment regimens, explore attitudes regarding physical health and treatment planning, and improve the ability of participants to return to work. The UIC-MAPS intervention comprises several components, including: (1) an educational workshop regarding health information, use of anti-retroviral medications, treatment planning, maintaining health, detecting early symptoms of illness progression, and other topics; (2) individualized medication plans; (3) meetings with clients and their identified sources of social support to address medication and services issues; and (4) hosting of monthly peer-led support groups on medication adherence, attitudes toward health and medication regimens, and issues related to health, well-being, and quality of life.

Find out more at: www.psych.uic.edu/mhsrp

Randomized Controlled Trial of Anti-Fatiguing Exercise to Improve Function in Multiple Sclerosis Patients, State University of New York (SUNY) at Buffalo (H133G010132)

led by Nadine M. Fisher, EdD. David W. Keer, Project Officer.

Abstract: The goals of this study are: (1) to measure the changes in fatigue that result from a simulated workday and the next morning (incomplete recovery and residual fatigue); and (2) to study the effectiveness of a 12-week program of anti-fatiguing resistance exercises. Multiple Sclerosis (MS) is a demyelinating disease of the central nervous system; the most common symptom of MS is a generalized sense of fatigue and reduced function. Few studies have considered the role of exercise as a treatment for fatigue in people with MS. Subjects with MS are randomly assigned an exercise group and receive an individualized progressive resistance training program of anti-fatiguing exercises to perform three days per week in the lab or at home.

Find out more at: php.buffalo.edu/rs/rehabphys

Rehabilitation Research and Training Center: Health and Wellness Consortium, Oregon Health and Science University (H133B990019)

led by Gloria Krahn, PhD. Theresa San Agustin, MD, Project Officer.

Abstract: The Center has a comprehensive program of research, training, technical assistance, and dissemination with primary attention given to the physical and mental aspects of health for people with long-lasting disabilities such as cerebral palsy, SCI, multiple sclerosis, amputation, and post-polio. Interconnected research areas include evaluating health assessment definitions, practices, policies, and measurement, and their impact on health promotion and investigating the relationship between selected health maintenance strategies and the incidence and severity of secondary conditions and other functional outcomes. Center projects examine the practices of exemplary generic and specialized health promotion programs; analyze the health behaviors and related functional outcomes of individuals with disabilities; examine the relationship between health definitions, practices, and

secondary conditions to develop a screening tool for health and wellness for people with disabilities; and investigate the association between disability and differential detection of cancer. The Center's third area of focus centers on identifying and evaluating best practices in health promotion. An additional



research focus is the use and efficacy of complimentary alternative medicine among people with these specific long-term disabilities. Find out more at: www.healthwellness.org

Depression and Rural Women with Disabilities: Testing a CIL-Based Self-Management Program, Baylor College of Medicine (H133G030170)

led by Rosemary B. Hughes, PhD. Bonnie Gracer, Project Officer.

Abstract: This project evaluates a depression self-management intervention for reducing and preventing depression in rural women with disabilities. The intervention is designed to increase participants' understanding and self-management of depression as it relates to experiences of secondary and chronic health problems, stress, lack of support, chronic pain, and abuse. This study is implemented in eight rural centers for independent living. The goals of this project are to (1) identify, address, and evaluate the mental health of rural women with physical disabilities, including women with newly recognized disabilities such as chronic fatigue immune deficiency syndrome and fibromyalgia; and (2) disseminate the findings to rural women with disabilities, rural independent living counselors, researchers, and mental health service providers.

Find out more at: www.bcm.tmc.edu/crowd

RehabWire for November focuses on "hidden disabilities" -- those conditions which, while debilitating, may not show visible symptoms.



December 1st is World AIDS Day, sponsored by the World Health Organization (www.unaids.org)

Selections from REHABDATA

Nijs, J., et al. (2003) **Psychometric properties of the Dutch chronic fatigue syndrome-activities and participation questionnaire (CFS-APQ)**. *Physical Therapy*, 83(5), 444-454. NARIC Accession Number: J45278.

Abstract: Study examined the convergent validity, content validity, and test-retest reliability of the Dutch-language version of the Chronic Fatigue Syndrome-Activities and Participation Questionnaire, an assessment tool for monitoring the activity limitations and participation restrictions of patients with chronic fatigue syndrome.

Greenwood, R. J., Barnes, M. P., McMillan, T. M., Ward, C. D. (Eds.) (2003) **Handbook of neurological rehabilitation**. NARIC Accession Number: R08358.

Abstract: An information resource for rehabilitation professionals who work with patients with neurological disorders. The book is divided into three sections. Section 1 discusses the clinical and biological principles underlying rehabilitation practice and mechanisms of recovery. Section 2 describes the assessment, treatment, and management of the major physical, cognitive, and behavioral impairment, and the functional deficits that may follow or accompany neurological disease. Section 3 discusses the management of specific disorders including multiple sclerosis, non-traumatic myelopathies, motor neuron disease, and muscle disorders.

Shannon, J. B. (Ed.) (2003) **Movement disorders sourcebook. Health reference series, first edition**. NARIC Accession Number: R08310.

Abstract: Book provides basic consumer health information about neurological movement disorders, including essential tremor, Parkinson's disease, dystonia, cerebral palsy, Huntington's disease, myasthenia gravis, multiple sclerosis, and other early-onset and adult-onset movement disorders, their symptoms and causes, diagnostic tests, and treatment. Includes mobility and assistive technology information, a glossary, and a directory of additional resources.

Dobkin, B. H. (2003) **The clinical science of neurologic rehabilitation**. NARIC Accession Number: R08362.

Abstract: Textbook provides basic information on medical complications and therapeutic approaches involved in the rehabilitation of patients with neurologic diseases. The management of common medical issues, impairments, and disabilities are described across diseases. Special problems posed by patients with stroke, myelopathies, brain injury, multiple sclerosis, degenerative diseases, and motor unit disorders are discussed. The second edition features entirely new chapters on functional neuroimaging of recovery, neurostimulators and neuroprostheses, and integration into the book of many new clinical assessment and outcome measures.

(2003) **Diagnosis: MS**. *PN/Paraplegia News*, 57(6), 32-36. NARIC Accession Number: J45538.

Abstract: Column provides updates treatments and ongoing research regarding multiple sclerosis (MS). Information is presented concerning: (1) pregnancy and the drug Copaxone, (2) racial differences in MS, and (3) the latest news on studies testing the safety and effectiveness of several experimental drugs and treatments.

Feys, P. G., et al. (2003) **Intention tremor rated according to different finger-to-nose test protocols: A survey**. *Archives of Physical Medicine and Rehabilitation*, 84(1), 79-82. NARIC Accession Number: J45006.

Abstract: Study investigated the influence of modified instruction for the finger-to-nose test (FNT) on the ratings of intention tremor in patients with multiple sclerosis. Patients performed the FNT according to four different test protocols. The instructions varied with regard to the required position of the arm and the time the finger had to be held on the nose. Six examiners rated the degree of intention tremor using the Fahn Tremor Rating Scale. Interrater reliability was high. Both the required arm position and time constraints affected the magnitude of intention tremor rating scores. Intention tremor was scored highest when the arm was lifted to 90 degree of abduction at the shoulder and the subject was required to stabilize the finger on the nose.

Feist-Price, S., Khanna, N. (2003) **School-to-work transition planning for school-aged children with HIV**. *Journal of Applied Rehabilitation Counseling*, 34(1), 10-16. NARIC Accession Number: J45333.

Abstract: Article discusses the psychosocial impact of HIV and AIDS on school-aged children, the purpose of transition services, collaborative transition planning, and ways the rehabilitation counselors can facilitate the school-to-work transition process.

Glenn, M. K., Ford, J., Moore, D., Hollar, D. (2003) **Employment issues as related by individuals living with HIV or AIDS**. *Journal of Rehabilitation*, 69(1), 30-36. NARIC Accession Number: J45131.

Abstract: Paper outlines issues that are confronting individuals living with HIV or AIDS as they consider returning to work. Surveys and interviews were conducted with people living with HIV or AIDS to provide rehabilitation counselors with a better understanding of the issues face in today's environment. Themes identified from the data include: changes in job status since diagnosis, reasons for not working, experiences when looking for employment, job search strategies, experience disclosing HIV status to employers, identified barriers, and recommended job accommodations.

Scheer, J., Kroll, T., Neri, M. T., Beatty, P. (2003) **Access barriers for person with disabilities: The consumer's perspective**. *Journal of Disability Policy Studies*, 13(4), 221-230. NARIC Accession Number: J45169.

Abstract: Article identifies access barriers to primary, specialist, and rehabilitative healthcare services for people with disabilities. Survey examined the experiences of people with spinal cord injury, cerebral palsy, or multiple sclerosis in getting access to needed healthcare services. Analysis of the data from the survey revealed three categories of barriers: (1) environmental barriers involving transportation, office, and equipment accessibility; (2) structural barriers, and (3) service delivery process barriers.

Schapiro, R. T. (2003) **Managing the symptoms of multiple sclerosis**. NARIC Accession Number: R08330.

Abstract: Provides an overview of the management of multiple sclerosis (MS), its symptoms, and the issues relating to lifestyle and general wellness for individuals with the disease. Book discusses every symptom of MS, including those affecting movement and walking, bladder and bowel, speech and swallowing, sensory disturbances, cognition and memory, and sexual difficulties. Author provides clinically tested methods for effective management of each symptom and discusses concerns regarding diet and nutrition, exercise, sexuality, and adapting to MS. A glossary of common medical terms, exercises for spasticity, tips for successful transfers and mobility, and a list of additional resources are included in the appendices.