

Research in the New Millenium

Rehabilitation Research and Training Center on Aging with a Disability, Los Amigos Research and Education Institute, Inc. (LAREI) (H133B980024) led by Bryan J. Kemp, PhD. Sean Sweeney, PhD, Project Officer.

Abstract: This project assists people who are aging with a disability by conducting a series of research studies using a database of over 1,000 people who represent a variety of disabilities (for example, cerebral palsy, rheumatoid arthritis, stroke, spinal cord injury, polio). Research projects include: (1) the natural course of aging with a disability; (2) assisting family caregivers of people aging with a disability; (3) improving community integration and adjustment; (4) prevention of secondary complications such as diabetes and thyroid disorders; (5) improving bone density through a regimen of exercise and vitamins; and (6) the effectiveness of assistive technology (AT) and environmental interventions (EI) in maintaining functional performance. Training, dissemination, and technical assistance activities focus on students and professionals in the health, allied health, and rehabilitation fields, as well as people aging with a disability and their families.

Find out more at: <http://www.agingwithdisability.org>

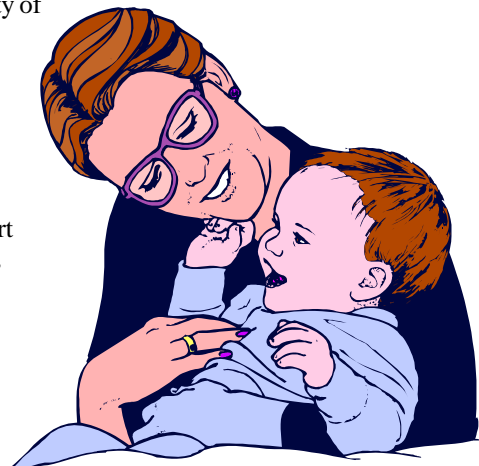
Developing and Evaluating Family Networks: Positive Behavioral Support, University of South Florida (H133G60119) led by Glen Dunlap, PhD and Bobbie Vaughn, PhD. Roseann Rafferty, Project Officer.

Abstract: The purpose of this project is to develop, demonstrate, and evaluate a program for building competent family networks concerned with challenging behaviors and developmental disabilities. Using a participatory training approach in collaboration with community agencies (e.g., Parent-to-Parent), the project is establishing family networks of reciprocal support. After the initial period of network development and training in behavioral support strategies, the project assists in the maintenance of network interactions and evaluates the short-term and longitudinal processes and outcomes associated with the network's interactions.

Find out more at: <http://lumpy.fmhi.usf.edu/CFSroot/dares/dares.html#anchor175096>

Rehabilitation Research and Training Center on Policies Affecting Families of Children with Disabilities, University of Kansas (H133B980050) led by Ann Turnbull, PhD and H. R. Turnbull, PhD. Roseann Rafferty, Project Officer.

Abstract: This project assesses policies and services and their impact on families' quality of life, focusing on four priorities: (1) developing an analytical framework for policy and service analysis; (2) developing measurement tools that apply state-of-the-art legal and policy analysis methodologies to the assessment of policies, service systems, and family outcomes; (3) identifying impacts of



partnership (including interagency collaboration and coordination) on family outcomes; and (4) conducting research with families from diverse backgrounds in several communities and states (Kansas, Louisiana, North Carolina).

Find out more at: <http://www.lsi.ukans.edu/beach/beachhp.htm>



A Family Intervention Following Traumatic Brain Injury in Children, Children's Hospital Medical Center (H133G990069) led by Shari L. Wade, PhD

Abstract: This project addresses the need for research into traumatic brain injury (TBI) in children and its impact on caregivers by developing and testing an intervention for families of children with moderate to severe TBI. The intervention is adapted from established problem-solving and communications skills training protocols that have been used successfully with families of children with chronic illnesses and behavior disorders. The study compares the effects of standard medical and psychosocial care to standard care plus the individualized problem-solving and communication intervention on the following outcomes: (1) injury-related stress and burden; and (2) caregiver psychological distress. The hypothesis is that better problem-solving and communication skills means less injury-related stress and better caregiver functioning among the intervention group compared to the standard care group. This outpatient intervention program is primarily targeted to reduce psychological disability in caregivers, thereby enabling the family to optimally support the child's recovery from TBI.



SHARE THE CARING
National Family Caregivers Month
November 1999

National Family Caregivers Month is sponsored by the National Family Caregiver Association (www.nfcares.org). Resources include tip and factsheets, articles, and brochures.

Additional resources:

Family Caregiver Alliance (www.caregiver.org), many factsheets, reading lists, and more.
The Well Spouse Foundation (www.wellspouse.org), a virtual community of spousal caregivers.
OUR-KIDS (listserv@maelstrom.stjohns.edu), a discussion list for caregivers of children with disabilities.
CARE-TBI (jlyon@driveninc.com), a discussion list for caregivers of people with TBI

Selections from REHABDATA

Elliott, T. R., Shewchuk, R. M. (1998) **Recognizing the family caregiver: Integral and formal members of the rehabilitation process.** *Journal of Vocational Rehabilitation*, V10, N2, p123-132. Accession Number: J35059.

Abstract: Article discussing societal and psychological issues regarding family caregivers, and ways to integrate them into the rehabilitation process. Topics include: personal costs of caregiving; the role of caregivers in adjustment to physical disability; caregiving in African American and other ethnic minority communities; and integrating the caregiver into the rehabilitation process.

Garwick, A. W., Kohrman, C., Wolman, C., Blum, R.W. (1998) **Families' recommendations for improving services for children with chronic conditions.** *Archives of Pediatric and Adolescent Medicine*, V152, p440-448. Rehabilitation Research and Training Project for Infants, Children, and Youth, Center for Children with Chronic Illness and Disability. Accession Number: J35244.

Abstract: Article about the effect of race/cultural background on family caregivers' views regarding services and programs for children with chronic conditions. Participants identified recommendations for improving the care of children with chronic conditions. Several African American and Hispanic families also suggested making information more culturally relevant and resources more accessible to families from diverse cultural backgrounds.

Allen-Kelsey, G. J. (1998) **Caregiver burden among African-American and Anglo-American family caregivers.** *Topics in Geriatric Rehabilitation*, V14, N1, p63-73. Accession Number: J35563.

Abstract: Article examining differences in predictors of caregiver burden among informal family caregivers of older adults in the African-American and Anglo-American populations. Data suggest that African-American caregivers perceive less burden than do Anglo-American caregivers, while providing more care to impaired elders.

Mintz, S. (1998) **Family caregivers: Healthcare's "glue."** *PN/Paraplegia News*, V52, N9, p64-68. Accession Number: J35699.

Abstract: Article on family caregivers, focusing on the importance of their role in the health care system, their feelings of burden, and the need for other family members to share their burden.

Braddock, D. (1999) **Aging and developmental disabilities: Demographic and policy issues affecting American families.** *Mental Retardation*, V37, N2, p155-161. University of Illinois/Chicago. Accession Number: J36655.

Abstract: Commentary discusses demographic and policy issues regarding aging and persons with developmental disabilities and their families. The author anticipates that growing demands for services, increased longevity, and the issue of waiting lists will increase pressure on family caregivers and makes recommendations

regarding future resource allocations concentrating on greater flexibility with Medicaid waivers, most specifically the Home and Community Based Services waiver program (HCBS).

Canam, C., Acom, S. (1999) **Quality of life for family caregivers of people with chronic health problems.** *Rehabilitation Nursing*, V24, N5, p192-196, 200. Accession Number: J37341.

Abstract: Article reviewing research on quality of life (QOL) in family caregivers of persons with chronic illnesses, and discussing related methodological issues, including the conceptualization and measurement of QOL.

Mintz, S. (1999) **Share the caring.** *PN/Paraplegia News*, V53, N9, p12-14. Accession Number: J37783.

Abstract: Article on the occasion of National Family Caregivers Month, emphasizing the need of family caregivers for help. Includes suggestions for religious congregations on how to support caregiving families.

Family members make up a significant portion of caregivers to people with disabilities. These caregivers are often left out of the rehabilitation equation. **RehabWire** for this Winter 1999 discusses the problems faced by family caregivers and solutions and resources to address them.

Grant, J. S. (1999) **Social problem-solving partnerships with family caregivers.** *Rehabilitation Nursing*, V24, N6, p254-260. Accession Number: J37871.

Abstract: Study comparing outcomes of social problem-solving partnerships for family caregivers of stroke patients using telephone contacts or home visits. The telephone group showed more improvement than the home visit or control groups. Some outcomes were affected by age, race, and education.

(1998) **Caregivers for SCI.** *Spinal Cord Injury - InfoSheet #17.* Rehabilitation Research and Training Center in Secondary Complications in Spinal Cord Injury, University of Alabama/Birmingham, Department of Physical Medicine and Rehabilitation. Available at <http://www.spinalcord.uab.edu>. Accession Number: O13066.

Abstract: Article addresses issues specific to caregivers, especially family caregivers, for survivors of spinal cord injury (SCI). An important finding was that on average caregivers experienced 3-4 more physical health problems during the first year. The Caregiver Stress Test is offered to help caregivers identify their stressors. Suggestions for handling stress related to each area of the test is included.

McFarlane, R., Bashe, P. (1998) *The Complete Bedside Companion: Nonsense Advice on Caring for the Seriously Ill.* Simon and Schuster, Rockefeller Center, 1230 Avenue of the Americas, New York, NY 10020. Accession Number: R07802.

Abstract: Book focusing on consumers and front-line service providers; outlines common concerns and caregiving strategies. Major topics include: strategies for effectively working with doctors and hospital staff; basic nursing and aide's skills and strategies; emotional and stamina considerations for family caregivers; strategies for involving other family members and soliciting community resources to relieve the caregiving burden; financial and legal concerns; and the facing of, and coping with, the death of a loved one. Disability-specific information is also provided. Includes annotated guide to resources.