

NIDRR Projects

Research in the New Millennium

RAICES/Promotoras, *University of South Florida* (H133G030014)

led by Mario Hernandez, PhD. Joyce Y. Caldwell, Project Officer. Abstract: RAICES (Resources, Advocacy, Integration, Collaboration, Empowerment, and Services) develops and tests a method of service provision that integrates a model known as Promotoras with a locally funded school-linked case management approach known as the Family and School Support Team (FASST). The RAICES project targets at-risk limited English speaking and Spanish monolingual Latino children or those with serious emotional disturbances enrolled in grades K-5 and their families in rural east and south Hillsborough County Florida. Promotoras, or community educators, are community members who use their knowledge of local resources and their neighborhood's health and social issues to promote healthy living and help community residents access needed health and social services.

Find out more at: cfs.fmhi.usf.edu/cfsnews/2003news/RAICES.htm

Rehabilitation Research and Training Center for Children's Mental Health,

University of South Florida

(H133B990022) led by Robert Friedman, PhD. Bonnie Gracer, Project Officer.

Abstract: This program examines policies affecting children with emotional disturbances and their families in order to enhance the understanding of policy development, its implementation, and effects. The consistency of state-level policy with system-of-care principles is examined through a series of related studies that address: family perspectives; interagency collaboration; school reform in urban communities; local theories of change and their relationship to services and outcomes; Medicaid managed care and the State Children's Health Insurance Program; the impact of managed care and system-of-care policies on access to care for children of color and their families; and development of a new instrument to assess interagency collaboration.

Find out more at: rtckids.fmhi.usf.edu

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.

Rehabilitation Research and Training Center on Policies Affecting Families of Children with Disabilities,

University of Kansas

(H133B031133) led by H.R. Turnbull, LLM and Ann Turnbull, EdD. Cate Miller, PhD, Project Officer.

Abstract: This center conducts eight research projects on the effects of the policies of governments, systems, networks, and agencies on

the family quality of life and community integration (FOOL/FCI) of families who have children with developmental disabilities and emotional-behavioral disabilities or both. Researchers identify four target populations: families, providers, policy-leaders, and networks. Three policy challenges are prisms through which the effects of policy on families can be understood: early intervention, alternative schools, and consumer control of funding. For each policy challenge, researchers inquire into whether the applicable federal and state policies and practices, and the applicable network policies, advance FOOL/FCI; whether the policies across education, social services, and health care are mutually consistent with each other and advance FOOL/FCI; and whether the practices of agencies in those systems advance FOOL/FCI.

Find out more at: www.beachcenter.org

Rehabilitation Research and Training Center to Improve Services for Children with Serious Emotional and Behavioral Disabilities and Their Families,

Portland State University (H133B990025) led by Barbara Friesen, PhD. Bonnie Gracer, Project Officer.

Abstract: This project conducts an integrated set of research, training, and technical activities to: (1) develop and evaluate service delivery models for children with an emotional disturbance and their families, including family-centered and culturally sensitive services; (2) define and evaluate the formal and informal components of

family support and identify successful family support interventions; (3) identify and evaluate early intervention strategies; and (4) identify, develop, and evaluate communication skills to enable families and service providers to communicate effectively with each other. Research issues include caregivers and employment, inclusive care, early intervention, education, service delivery, training, and mentoring.

Find out more at: www.rtc.pdx.edu

Multi-Family Group Intervention for Traumatic Brain Injury and Spinal Cord Injury Patients and Families,

Inland Northwest Health Service (H133G020006) led by Bruce Becker, MD. Richard E. Wilson II, EdD, Project Officer.

Abstract: This project establishes two SCI and two TBI multi-family group (MFG) interventions to support and teach families and patients about the disability process and management strategies. MFG is a structured management strategy that has been extensively tested in the management of chronic schizophrenia and more recently adapted for other chronic disabling conditions. This strategy brings together groups of six to eight families with two MFG group clinician/facilitators in a psycho-educational problem-solving format, over a period of 18 months. Families are given the opportunity to discover and share problems and solutions about the process of living with other families and patients through the implementation of practical guidelines for effective coping. The intervention has been highly effective in reducing relapse and hospitalizations, and improving symptom control and quality of life, for persons with schizophrenia. This project compares TBI and SCI MFG groups for ease of implementation, efficacy (process and outcome), and cost, adapting measures previously studied in schizophrenia with those used in assessing family stress in SCI and TBI.

RehabWire for December looks at families and the issues they confront in dealing with disabilities.



Selections from REHABDATA

King, G., Law, M., King, S., Rosenbaum, P., Kertoy, M. K., Young, N. L. (2003) **A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities.** *Physical and Occupational Therapy in Pediatrics*, 23(1), 63-90. Accession Number: J45328.

Abstract: Article presents a conceptual model of 11 environmental, family, and child factors that may influence participation in recreation and leisure activities by children with disabilities. Three major environmental factors were identified: (1) supportive physical and institutional environments, (2) supportive relationships for the child, and (3) supportive relationships for the parents. Four family factors were indicated: (1) absence of financial and time constraints caused by having a child with a disability, (2) supportive family demographics, (3) supportive home environment, and (4) family preference for recreation. Also, four key child factors were included in the model: (1) children's own view of their competence; (2) their cognitive, physical, and communicative function; (3) their emotional, behavioral, and social function; and (4) their activity preferences.

Franz, J. P. (2003) **No more Clarences: Creating a consistent and functional multisystem resource for children with complex needs and their families.** *Journal of Disability Policy Studies*, 13(4), 244-253. Accession Number: J45171.

Abstract: Fictional case illustrates the challenges communities face when existing services are unable to provide support for children with complex needs and their families. Various programs developed to address these problems are described, but most have not produced reliable outcome. Author proposes using the lessons learned from those programs to build a model that integrates changes at the practice, administrative, system, and community levels as a way of ensuring availability of effective services.

Harris, S. L., Glasberg, B. A. (2003) **Siblings of children with autism: A guide for families.** Accession Number: R08329.

Abstract: Book examines what it's like to grow up as a sibling of a child with autism. Provides information to parents regarding how to explain autism to siblings, how to help siblings share their feelings, and how to balance the needs of the entire family. Includes a chapter about the concerns and responsibilities of adult siblings.

Wagner, D. L. (2003) **Workplace programs for family caregivers: Good business and good practice.** Accession Number: R08380.

Abstract: Paper examines issues faced by family caregivers who are employed. Discusses efforts made by employers to address these issues, presents models of workplace programs, and describes promising partnerships developing between employers and service providers.

Sander, A. M., Sherer, M., Malec, J. F., High, W. M. Jr., Thompson, R. N., Moessner, A. M., Josey, J. (2003) **Preinjury emotional and family functioning in caregivers of persons with traumatic brain injury.** *Archives of Physical Medicine and Rehabilitation*, 84(2), 197-203. Accession Number: J45024.

Abstract: Study examines the preinjury family functioning, emotional distress, and social support of caregivers of persons with TBI. Caregivers were assessed using the following self-report questionnaires: the Brief Symptom Inventory, the Family Assessment Device, and the Multidimensional Scale of Perceived Social Support. Histories of medical and psychiatric illness were

also obtained. Thirty-seven percent of caregivers indicated symptoms of emotional distress, while 27 percent reported a history of mental health problems. Between 25 and 33 percent of caregivers reported unhealthy family functioning before injury. Ninety-two percent of caregivers reported overall satisfaction with the social support they received.

Dyson, L. L. (2003) **Children with learning disabilities within the family context: A comparison with siblings in global self-concept, academic self-perception, and social competence.** *Learning Disabilities Research and Practice*, 18(1), 1-9. Accession Number: J45118.

Abstract: Study compares the global self-concept, academic self-concept, and social competence of children with learning disabilities (LD) with their non-LD siblings within the family context. Participants were administered child assessment tests and rated by their parents. Results indicated no significant difference between children with LD and their sibling in global and academic self-concept. However, parents rated their children with LD as having less social competence and more behavior problems than their siblings. Further, the social and behavioral competence of children with LD was associated with parental stress and family functioning.

Lincoln, N. B., Francis, V. M., Lilley, S. A., Sharma, J. C., Summerfield, M. (2003) **Evaluation of a stroke family support organizer: A randomized controlled trial.** *Stroke*, 34(1), 116-121. Accession Number: J44922.

Abstract: Study evaluates the effectiveness of the Stroke Family Support Organizer (FSO) service. Stroke patients and their caregivers were randomly assigned to receive the FSO service or standard care. Outcomes were assessed at 4 and 9 months after recruitment with the General Health Questionnaire 12, the Carer Strain Index, the Barthel Index, the Extended Activities of Daily Living scale, and a questionnaire designed specifically to determine knowledge of stroke and satisfaction with services. Patients and caregivers in the FSO intervention group were more satisfied with the stroke information they received and were significantly more knowledgeable about whom to contact for stroke information, reducing the risk of stroke, practical help, community services, and emotional support. The FSO service has no significant effect on mood, independence in activities of daily living, or reduction in caregiver strain.

Levy, J. M. (2003) **Promoting family health and resilience.** *Exceptional Parent*, 33(2), 54-57. Accession Number: J45091.

Abstract: Article presents guidelines for reducing stress and promoting family wellness for parents who have a child with a disability. Strategies discussed include (1) parents considering their own needs first; (2) taking time for rest, relaxation, and recuperation; (3) practicing resilient behaviors; (4) dealing with guilt and anger; (5) developing coping strategies; (6) involving siblings; and (7) taking an inventory of stress triggers.

The staff of NARIC wish you and your family all the warmth and joy of the season and peace in the year to come.

