The booklet provides information on current family-oriented research activities based on a survey of 16 Rehabilitation Research and Training Centers and 17 projects funded by the National Institute on Disability Research or other agencies. Information provided for each center includes name, address, phone number, director, funding source and period, a brief description of the center, brief descriptions of each of the center's projects, and a listing of center and project publications. Centers are listed alphabetically by state; projects connected with universities alphabetically by name of the university; and miscellaneous projects alphabetically. A feedback sheet is provided to encourage additional or corrected information for further editions. (DB)
Call to the Field:
Research on Families and Disability
1988-1989

May 1989

Prepared by:
Harriet Shaffer
Julie Cross

Prepared under a grant from the National Institute on Disability and Rehabilitation Research

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The University of Kansas
Bureau of Child Research
4138 Haworth Hall
Lawrence, KS 66045
Table of Contents

Introduction ......................................................... i

I. Rehabilitation Research and Training Centers
   (in alphabetical order, by state)

   ALABAMA
   Spain Rehabilitation Center: Rehabilitation Research & Training Center in the Prevention and Treatment of Spinal Cord Injury ......................... 1

   ARIZONA
   American Indian Rehabilitation Research & Training Center .................. 3

   CALIFORNIA
   Rehabilitation Research & Training Center in Progressive Neuromuscular Diseases .......................................................... 5

   CONNECTICUT
   Pediatric Research & Training Center ........................................ 7

   FLORIDA
   Research & Training Center for Children’s Mental Mental Health Center .......................................................... 9

   HAWAII
   Pacific Basin Rehabilitation Research & Training Center ................. 11

   KANSAS
   Beach Center on Families & Disability ...................................... 13

   MASSACHUSETTS
   Research & Training Center in Childhood Trauma & Rehabilitation ........ 18

   NEW YORK
   Research & Training Center for the Psychiatrically Disabled .................. 20

   Rehabilitation Research & Training Center on Community Integration of Persons with Traumatic Brain Injury ............................... 22

   OREGON
   Rehabilitation Research & Training Center to Improve Services for Seriously Emotionally Handicapped Children and Their Families ............ 24

   TEXAS
   ILRU Research & Training Center on Independent Living at TIRR ............. 26
TEXAS (continued)
Rehabilitation Research & Training Center in
Community-Oriented Services for Persons with
Spinal Cord Injury. .......................... 28

VIRGINIA
Rehabilitation Research & Training Center on
Supported Employment. ...................... 30
Rehabilitation Research & Training Center on Severe
Traumatic Brain Injury. ....................... 32

WISCONSIN
Rehabilitation Research & Training Center:
Consortium on Aging & Developmental Disabilities. .... 34

II. Projects Connected with Universities (not R & T Centers)
(in alphabetical order by name of the University or the project)

Brown University .......................... 36
Illinois UAP ................................. 39
New York University Medical Center .................. 41
Oregon State System of Higher Education. ............ 43
State University of New York, Binghamton ............. 45
University of Arkansas, Little Rock
Center for Research on Teaching & Learning ............ 47
University of California, Los Angeles
Department of Psychology ........................ 49
University of California, Los Angeles
Clinic for the Behavioral Treatment of Children. ........ 51
University of California, Santa Barbara. ............... 53
University of Kansas
Institute for Research in Learning Disabilities. ........ 55
University of North Carolina
Frank Porter Graham Child Development Center ........ 57
University of Oregon
Specialized Training Program ........................ 59
University of Pittsburgh
Western Pennsylvania School for the Blind. ............. 61
III. Miscellaneous Projects

<table>
<thead>
<tr>
<th>Organization</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Human Services Research Institute</td>
<td>63</td>
</tr>
<tr>
<td>New York State Head Injury Association</td>
<td>65</td>
</tr>
<tr>
<td>PEAK Parent Center, Inc.</td>
<td>67</td>
</tr>
<tr>
<td>TEACCH Program</td>
<td>69</td>
</tr>
<tr>
<td>Through the Looking Glass</td>
<td>71</td>
</tr>
<tr>
<td>FEEDBACK SHEET</td>
<td>73</td>
</tr>
</tbody>
</table>
INTRODUCTION

WHAT IS THE PURPOSE OF THIS BOOKLET?

In this booklet, we at the Beach Center on Families and Disability provide you with information about family-oriented research activities nationwide. This information has been reported to us in response to our Center’s "Call to the Field" to 38 Rehabilitation Research and Training Centers, and 92 other projects primarily funded by the National Institute on Disability Research, as well as some funded by other agencies. In addition, some responses were received in response to a mailing about a conference on value-based family research held by the Beach Center for Families and Disability, May 5 - 7, 1989, in Washington, D.C. Responses were received from 16 Research and Training Centers and 17 other projects. Our purpose is to provide you with this information as a means of establishing an information exchange and as a way of establishing collaborative networking among researchers with interests in families and disabilities. Since the Beach Center on Families and Disability has as its main emphasis the effects of disability on the family, we see one of our missions as that of providing information to researchers nationwide about work being done in relation to families and disability.

WHAT IS FAMILY RESEARCH?

By "research on families and disability" we are referring to basic, applied, or policy research that investigates variables related either to the family as a whole or to a relative (e.g., parent, spouse, sibling) of a person with a disability. We are not including research related to an individual with a disability per se, unless that research is focusing on some aspect of the person’s interactions with his or her family. We define a family member as anyone related by blood, marriage, adoption, foster-family status or long-term association.

HOW IS THIS MATERIAL ORGANIZED?

We want to make it clear that we are using information provided to us by the particular project in response to our "Call to the Field". Thus, we are including only information from projects that responded to our request. We plan for this booklet to be a publication of our Center in 1989, 1991, and 1993; thus, we plan in future years for the number of projects described to increase. If you receive this booklet and information about your Center or project is not included and you would like it to be included in the future, please let us know so that we can contact you next year. We hope that this booklet is of use to you; we welcome your input and feedback and have included a feedback page for your use. Please let us know if we have not described your project or Center correctly. In most cases, we used the description provided by your Center or project; if there was no such description, we used the description of the Center or project provided in the NARRTC Directory (1988) or the NIDRR Directory (1989). We appreciate the feedback we received on our "Call to the Field letter"; that feedback will help us to be more specific in our requests next year.
We are providing descriptive information about each project. In addition, many Centers and projects mailed us copies of publications as well as copies of research instruments. Thus, we are including information on published materials (i.e., specific citations) as well as information on materials published by the particular Center or project. Here again, we included information about publications only if copies of the publications were mailed to us.

You may contact the project directly at the address or phone number provided if you wish further information about a particular Center, project, or publication.
Spain Rehabilitation Center

Rehabilitation Research & Training Center in the Prevention and Treatment of Spinal Cord Injury
University of Alabama
University Station, 1717 6th Ave., S.
Birmingham, AL 35294
(205) 934-3334

Project Director: Samuel L. Stover, M.D.
Research Director: J. Scott Richards, Ph.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 6/88 - 5/93

Center Description
The goal of the Center is to improve rehabilitation management of persons with spinal cord injury. The Center conducts basic and clinical research into new methods and techniques to prevent and treat complications occurring in persons with spinal cord injury.

Project Name
Medical and Psychological Considerations Regarding the Surgical or Pharmacological Treatment of Impotence in Males with SCI

Project Description
People with SCI seeking treatment for sexual dysfunction will be offered either a penile implant or injections to try & improve erectile function. This study, using tests of sexual behavior and satisfaction, will determine if these options are helpful and are worth the associated risks.

Project Name
A Longitudinal and Cross-Sectional Analysis of Well-Being in Persons with Spinal Cord Injury and Their Caregivers

Project Description
This study will examine the quality of life for both people with SCI and their primary caregivers at several intervals post-injury.

Project Name
Outcomes of Post-Spinal Cord Injury Marriages

Project Description
This study followed 410 persons injured since 1973 and enrolled in the National Spinal Cord Injury Statistical Center data base who get married after their injury. Results suggest that the impact of SCI on post-injury marriages is almost as substantial as it is on pre-existing marriages.
Spain Rehabilitation Center:
Rehabilitation Research & Training Center in the Prevention and Treatment of Spinal Cord Injury

Publications:


Center Publication:

2. What is SCI? An Elementary Overview (6/89 - 5/91)
3. A Handbook of Self-Care for People with SCI (6/89 - 5/91)
4. Preventing Secondary Complications: Do's and Don'ts for Personal Care Attendants of People with SCI (6/90 - 5/91)
5. Research Update for People with SCI (6/90 - 12/92)
American Indian Rehabilitation Research & Training Center

Northern Arizona University, Inst. for Human Development
Box 5630
Flagstaff, AZ 86011-5630
(602) 523-4791

Project Director: Charlotte Tsoi Goodluck, MSW
Research Director: William E. Martin Jr., Ed.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 1988-1993

Center Description
The Center conducts research and training that supports rehabilitation and
special education services for American Indians. Projects include those in the
areas of: (a) job development on and near reservations using local labor market
analyses and model job training programs, (b) investigation of culturally
sensitive rehabilitation strategies, (c) community systems analyses through
consumer involvement and (d) investigation of specific types of disabilities
that are of significant concern to American Indian people.

Project Name
Utilization of Genograms and Eco-maps to Assess American Indian Families Who
Have a Member with a Disability (Making Visible the Invisible)

Project Description
This project will investigate the utility of the genogram & eco-map as family
assessment tools for working with American Indian VR clients referred for
disability services & to describe changes in the family after VR services by
evaluating information in the genogram and eco-maps at the beginning and end of
the service.
American Indian Rehabilitation Research & Training Center

Center Publications:

1. Utilization of Genograms and Eco-maps to Access American Indian Families who have a Member with a Disability (Project R-18)
Center Description
The Center conducts a broad-based, multidisciplinary program of research in the area of comprehensive rehabilitation management of neuromuscular diseases. It initiates training that transposes research findings into tangible products that rehabilitation practitioners and educators can use in service delivery and teaching programs. The goal of all research projects is to identify factors that prevent or limit successful rehabilitation and to develop intervention strategies to overcome those limiting factors.

Project Name
Student Education Questionnaire

Project Description
Summer camp attendees participated in a pilot assessment of educational needs. A questionnaire to survey parents' impressions of the educational system is in preparation.

Project Name
Development of Rehab. Options to Improve Vocational, Educational and Independent Living Options in Progressive Neuromuscular Diseases

Project Description
No description provided.
Rehabilitation Research & Training Center in Progressive Neuromuscular Diseases

Center Publications:

1. Neuromuscular Disease: Patient Education Program, (Grant No. G008300078) April 25, 1987, flyer

Pediatric Research & Training Center

Univ. of Connecticut Health Center/ Child & Family Studies
The Exchange
Farmington, CT 06032
(203) 674-1485

Project Director: Mary Beth Bruder, Ph.D.
Research Director: Gerald Mahoney

Funding Agency: U.S. Department of Education, Office of Special Education
Funding Period: 4/84 - 4/89

Center Description
The Center is dedicated to the habilitation and rehabilitation of all children with disabilities with special emphasis on birth-to-five. Research and training activities of the Center focus on family services and community-based programs. The Center addresses the needs of the target population through community-identified initiatives and the development of strong working relationships with state and private resource organizations.

Project Name
Interactions between mothers and their handicapped children: A longitudinal study

Project Description
This investigation was conducted to identify patterns of material communication with young children with mental retardation and to determine how these patterns of the mother relate to the communicative competence of the child.

Project Name
A National Study of the Practices of Early Intervention Service Providers

Project Description
This is a study of almost 1000 professionals from six states who were working in intervention programs from birth to six year old children with disabilities and their families to gain the perspective of these service providers.

Project Name
Maternal Perceptions of Family Focused Early Intervention Services

Project Description
A questionnaire was completed by a sample of 503 mothers of birth to 6-yr old children with disabilities enrolled in intervention programs throughout the U.S. The questionnaire was designed to identify types of family intervention services mothers were currently receiving and the types they would like to obtain.
Pediatric Research & Training Center

Publications:


Center Publications:


Project Name
NACTS, National Adolescent & Child Treatment Survey

Project Description
The NACTS is a nationwide, four-year, sequential cohort study of 960 children with serious emotional problems. Goals of the study are to describe the characteristics and problems of the children and their families, determine the types of services they receive, and describe how the problems and services change over time.
Research & Training Center for Children's Mental Health

Center Publications:

1. Annotated Bibliography - describes material prepared by staff of Florida Mental Health Institute, University of South Florida.

2. Family Functioning and Psychopathology Among SED Adolescents - Draft

3. "The Diagnostic Interview Schedule For Children: A Study of Its Utility with Children and Adolescents Identified as Emotionally Disturbed by Mental Health and Special Education Systems" (1988)


5. National Adolescent and Child Treatment Survey, Parent Interview
Center Description
The goal is to improve services provided to persons with disabilities through rehab. research and training in the Pacific Basin and to assist in the coordination of medical, educational, and vocational rehabilitation services. Objectives are to develop a sound demographic base, collect and analyze data on incidence and prevalence of disability, develop culturally relevant rehabilitation programs using appropriate technology, and assess rehabilitation personnel needs for manpower training.

Project Name
Assessment of Individual Functioning, Care Providers and Customary Environment

Project Description
We are considering the total context in which individuals with disabilities operate, as well as attitudes, skills and knowledge of their care provider(s) and important aspects of their physical home and work environments.
Center Publications:

No publications were directly provided to the Beach Center.
Center Description
The Beach Center’s primary concerns in its research, dissemination and training activities are those of families with a member with a disability. The Beach Center believes that persons with disabilities contribute positively to their families, that families should have great expectations for the future, that persons with disabilities are entitled to full citizenship, that families should have choices, that relationships are crucial to family unity, and that families have inherent strengths.

Project Name
Assessment of Strengths and Needs in Families with Children with Developmental Disabilities

Project Description
The purposes of this research are to 1) identify family & provider opinions concerning preferred processes to incorporate state-of-the-art values into the process for developing IFSPs & identify expected outcomes for families of early intervention; 2) design & investigate a model procedure for developing IFSPs that combines preferences & opinions.

Project Name
Permanency Planning: A One-Year Planning Study

Project Description
The purpose of this project was to plan the research agenda for future activities. Staff members have carried out that purpose by conducting a literature review, meeting with consultants, developing a proposed two-pronged research plan on reasonable efforts, and developing drafts of recommendations for policy reform.

Project Name
Assisting Families of Participants in Adult Day Care

Project Description
This project is based on 2 reviews of caregiving research with the objective of providing an overview of ‘what works’ to assist caregivers, and also to point to promising practices that are in the process of being developed or might be developed.
Beach Center on Families and Disability

Project Name
An Evaluation of Family Decisions to Provide Home-Based vs. Hospital-Based Care for Technology Dependent Children

Project Description
This research has resulted in an extensive literature review concerning children who are supported by technology and their families, a draft of an article for school administrators about the placement of such children in regular settings, a draft of an article for school nurses about the education of these children, and a plan for research on family-school interactions related to the educational outcomes for these children and the provision of related services in regular education settings.

Project Name
Research on Behavior Assessment & Behavioral Intervention in Competence in Decision-Making by the Adolescent/Adult with a Disability: Expression of Preference by Adolescent/Adult with a Disability and/or Other Members of the Family

Project Description
The purpose of this research is to develop a model and an assessment system based on the model that will allow a family or a family support worker to identify positive and negative experiences resulting from the presence of the adolescent/adult with a disability in the family structure. In addition, the assessment system will determine the way families respond to these positive and negative experiences. This will be followed by the design of specific interventions intended to result in increasing or at least ensuring the maintenance of positive experiences and decreasing or at least reducing the intensity of negative experiences.

Project Name
Research on Behavioral Assessment and Behavioral Interventions in (A) Competence in Decision-Making by the Adolescent/Adult with a Disability; (B) Expression of Preferences by Adolescent/Adult with a Disability and/or Other Members of the Family

Project Description
The purpose of this research is to evaluate competency assessment and expression of preference as two aspects of the future planning model developed by Turnbull, Turnbull, Bronicki, Summers, and Roeder-Gordon (1989). This model encourages planning that, to the greatest extent possible, is based on the choices and preferences of the person with the disability but also considers the needs of the whole family and involves current and potential service providers, supporters, and anyone else who has an interest in the family member with a disability.
Beach Center on Families and Disability

Project Name
Research on Qualitative Assessment of the Impact on the Members of a Social Fraternity of Being Hosts to a Young Man with Developmental Disabilities

Project Description
Using the pentad inquiry structure, the purpose of the proposed study is to learn about facilitators by conducting and interpreting interviews with reference to: Who would facilitate in the social life of a person with mental retardation? What (and how) do they facilitate within that individual’s social lifestyle? Why, when and where are those facilitating functions performed?

Project Name
The Family Enhancement Program: The Development and Evaluation of a Multi-Component Family Treatment Program

Project Description
The goal is to develop, implement, and evaluate an in-home, multi-component family treatment program for families of adolescents with emotional disorders. The ultimate purpose is to do research that helps families remain as integral units with optimum methods of functioning, help prevent out-of-home placement of youths with severe disturbance, and help build social skill competencies for all family members.

Project Name
Cognitive Adaptations Interventions Strategies

Project Description
The purpose of this research is to examine the effectiveness of interventions designed to increase the use of cognitive adaptations coping strategies. Specific research questions are whether the frequency of use of coping strategies increases after intervention and whether increased frequency of use of coping strategies is associated with decreased stress of improved family well-being?

Project Name
Plan and Conduct a National Survey and Impact Study of the Parent to Parent Support Programs

Project Description
The purpose of the Parent to Parent National Survey Project is to gather information about the Parent to Parent network as a first step toward developing an empirically based evaluation of Parent to Parent programs. Because the number of programs utilizing a Parent to Parent model as a component of the services provided is unknown, as is the effectiveness of the model on a broad scale, in order to fully understand the scope of the network and the success of the approach, there is a need to collect descriptive data.

Project Description
The purpose of the research was to study the implementation of P.L. 99-319 with respect to the goal of deinstitutionalization of children with emotional disabilities.
Beach Center on Families and Disability

Center Publications:

1. Brochure, Beach Center on Families & Disability
2. Newsletter, Families & Disability, (3 times annually, first issue 5/89)
3. Publications Catalog, 6/89

Publications:


Childhood injury is a largely unknown disorder, yet trauma is the leading cause of death and disability in children. The Tufts-NEMC RTC is developing and disseminating an information base that describes the natural history of childhood trauma and its consequences. Methods of identifying and measuring the benefits of specific intervention strategies are being developed.

Project Name: Pediatric Evaluation of Disability Inventory

Project Description: This is a pilot study with the purpose of establishing reliability and validity in year 1, and of standardizing the instrument on 700 children without disabilities in year 2.
Research and Training Center in Childhood Trauma and Rehabilitation

Center Publications:


2. Pediatric Evaluation of Disability Inventory (Versions-Draft 10, Draft 2)
Research & Training Center for the Psychiatrically Disabled

Psychiatric Institute

Albert Einstein College of Medicine
722 W 168th Street/ Box 111, Rm. 212
New York, NY 10032
(212) 960-2554

Project Director: William McFarlane, M.D.
Research Director: William McFarlane, M.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 9/30/85 - 9/29/90

Center Description
The focus of the Center is to improve and maintain the rehabilitation of individuals with psychiatric disabilities. The program consists of interrelated research and training projects in three areas: vocational rehabilitation outcomes; development of standardized disability determinations; and rehabilitation interventions in the home, community and criminal justice system.

Project Name
Psychoeducational Multiple Family Intervention for Schizophrenia in the Altro Vocational Rehabilitation Setting

Project Description
The goal of this project is to test a psychosocial intervention for schizophrenia in the Altro Health & Rehabilitation Services. This project involves a family psychoeducational approach.
Research & Training Center for the Psychiatrically Disabled

Center Publications:

No publications were directly provided to the Beach Center.
Center Description
The Center conducts: 1) studies relating to effective mechanisms of community integration and 2) a training and information dissemination program for professionals and families of persons with traumatic brain injury (TBI). The Center seeks to empower consumers, families, and TBI advocacy organizations.

Project Name
Model Family-Professional Partnership Interventions for Childhood Traumatic Brain Injury Survivors

Project Description
This project addresses the social, psychological & economic impact of traumatic brain injury on families of children up to age 16 by developing & evaluating techniques for family involvement in the treatment, education, &/or rehabilitation process with incentives & disincentives to family involvement. (With the NY State Head Injury Assoc.)
Rehabilitation Research and Training Center on Community Integration of Persons with Traumatic Brain Injury

Center Publications:

1. Brochure on RRTC on TBI.

Rehabilitation Research & Training Center to Improve Services for Seriously Emotionally Handicapped Children & Their Families
Regional Research Institute

Portland State University
P.O. Box 751
Portland, OR 97207-0751
(503) 464-4040

Project Director: Barbara J. Friesen, Ph.D.
Research Director: Richard Vosler-Hunter, M.S.W.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 10/84 - 9/89

Center Description
The Center's purpose is to conduct research on ways of improving services to help children with emotional disturbances live at home, learn in school, and succeed at paid employment; to develop training materials and programs for professionals, parents, and employers; and to serve as a resource center for other individuals and organizations working on behalf of children with emotional disabilities and their families.

Project Name
Survey of Parents of Children with Emotional Handicaps

Project Description
This survey was designed to gather information about parents' needs, experiences with obtaining services and needed information, sources of support and effects on family life.
Families as Allies, Research & Training Center to Improve Services to Seriously Emotionally Handicapped Children & Their Families

Center Publications:

1. Parent Survey (1987)
4. Focal Point (newsletter, 4 issues annually)
5. Annotated Bibliography on Therapeutic Methods (1988)
Center Description

The purpose of the Center is to promote the independence of persons with disabilities through research, training, and technical assistance activities focused on service providers.

Project Name

Study of Personal Assistance Service for Persons with Severe Disabilities

Project Description

This will examine existing types of helping systems and attempt to reach a new understanding about how the adequacy of personal assistance services determines functioning and quality of life of persons with severe disabilities and how their need for those services can best be met.
ILRU Research and Training Center on Independent Living at TIRR

Center Publications:

No publications were directly provided to the Beach Center.
Center Description
The Center conducts a coordinated program of research, training, and service demonstrations that has the goal of improving the health maintenance, psychological adjustment, and community integration of persons with spinal cord injury who have resumed their lives in the community after receiving acute rehabilitation services. A corollary goal of the Center is to develop further understanding of the aging process of persons with spinal cord injury.

Project Name
The Influence of Caregiver Well-Being on Outcomes for Persons with Spinal Cord Injury

Project Description
This study will cross-validate previous findings and research other areas of life in addition to psychological well-being for both the caregiver and the person with spinal cord injury; the main focus will be on the impact of the well-being of the caregiver on the outcomes of the injured person.

Project Name
The Daily Activities of Caregivers Living with Disabled Persons

Project Description
This study will describe activities of wives and mothers in the transition of their sons or husbands with SCI into the home environment after discharge from medical care. It indicates the feasibility of using the SORT (Self-Observation and Report Technique) for measuring the impact of SCI on the caregiver in future studies.
Baylor College of Medicine

Center Publications:

No publications were directly provided to the Beach Center.
The mission of the Virginia Commonwealth University Rehabilitation Research and Training Center (VCU-RRTC) is to provide research, training, and leadership related to the supported employment of citizens with developmental and other severe disabilities.

Project Name
The Effect of Various Parent Educational Strategies on Parents’ Knowledge of Pref. for & Satisfaction with Support Employment Services

Project Description
The purpose of this study is to investigate the effects of training and information that parents of individuals with severe disabilities receive about transition from school to work. This is being done in cooperation with PEATC (Parent Educational Advocacy Training Center).
Rehabilitation Research & Training Center on Supported Employment

Center Publications:

No publications were directly provided to Beach Center.
Center Description
The Center conducts relevant research & training on diagnosis and rehabilitation of persons with severe traumatic brain injury. Research includes investigations of hydrocephalus, pathophysiology of brain function, coma, memory disorders, family reactions to injury, outcome in children, & strategies for improvement of vocational outcomes. Training projects include development & collection of materials for inclusion in a National Clearinghouse of Information and specialized training programs relevant to TBI for multidisciplinary training professionals.

Project Name
Family Research Project

Project Description
The primary purpose of this project is to provide longitudinal information regarding family needs and reactions to brain injury. Objectives include assessment of changes in family perceptions of needs over time; the extent to which primary caregivers report significant levels of psychological distress at different times post-injury.
Rehabilitation Research & Training Center on Severe Traumatic Brain Injury

Center Publications:

Rehabilitation Research & Training Center
Consortium on Aging & Developmental Disabilities
Walsman Center
University of Wisconsin-Madison
Madison, WI 53705
(608) 263-2966

Project Director: Gary Seltzer, Ph.D.
Research Director:

Funding Agency: No information provided.
Funding Period: No information provided.

Center Description
The Wisconsin section of the initial NIDRR proposal was written with the intent of investigating the psychosocial and health status of caregivers of older persons with developmental disabilities.

Project Name
First

Project Description
This project is a short-term support and educational interventional targeted to enhancing the quality of relationships that families and other caregivers have with their formal and informal social supports.

Project Name
Second

Project Description
This project includes a diagnostic clinic for aging persons with developmental disabilities.

Project Name
Third

Project Description
This project is a collaborative one on aging families with sons or daughters with mental retardation.
Rehabilitation Research & Training Center

No publications were directly provided to the Beach Center.
Project Name
Multi-Center Stroke Study: Family Functioning, Health Status, Morale & Functional Capacity in Stroke Patients

Project Description
This study looks at the levels of family functioning, health status, morale and functional capacity in stroke patients and their families at four sites. All sites use a standardized protocol.

Project Name
Parkinsonism: Family Functioning, Functional Capacity, Depression and Health Status

Project Description
Family functioning, functional capacity, morale and health status data are being gathered on a population of Parkinson Disease patients and their spouses. These findings will be compared to data on patients with strokes.

Project Name
Male and Female Differences in Perception of Family Functioning

Project Description
This study compared couples with no illness, couples with one member in the family having a psychiatric illness and couples with one family member having a chronic illness or disability as to whether or not a husband and wife identify the same issues when asked to describe or reflect on the family.
Project Name
Family Functioning and Suicidality

Project Description
This study focuses on patients with major depression and on psychosocial correlates of suicidality. It discussed whether or not there are differences in family functioning between families of suicidal family and nonsuicidal depressed inpatients.

Project Name
Family Functioning: Reliability Validity

Project Description
This instrument is undergoing psychometric assessment.
Brown University

Center Publications:


2. Videos:
   - McMaster Model of Family Functioning (1 hour)
   - Problem-Center Systems Therapy (3/4 hour)
   - Disability and the Family (1 hour)
   - Family Assessment (1 hour)

3. Family Instruments
   - McMaster Family Assessment Drive
   - McMaster Clinical Rating Scale
   - McMaster Structured Interview of Family Functioning
   - Manual for McMaster Problem Solving Systems Therapy of the Family
Center Description

Project Name
Domestic Cycle Project

Project Description
This project is designed to investigate relationships between families who have family members with mental retardation relative to families without members with mental retardation.

Project Name
Transition Plan for Person with Developmental Disabilities Residing in the Natural Home with Elderly Parents

Project Description
The purpose of this project was to develop a plan for these adults by assessing the needs and attitudes of families and by examining related service system and policy issues.

Project Name
Transition for Older Adults with Developmental Disabilities: Facilitating Family and Resident Adjustment

Project Description
This project will examine the major concerns of families and residents undergoing transitions to identify guidelines for lessening any trauma or crisis.
Illinois UAP

Publications:

Center Publications:
1. Heller, T., & Factor, A. Transition plan for persons with developmental disabilities residing in the natural home with elderly parents.
2. Heller, T., & Factor, A. GPCDD transition plan study: Interview plan study.
3. Rowitz, L., Heller, T., & Farber, B. Domestic cycle project: Primary caregiver interview.
Project Name
(Hi-Fi) The New York University Head Injury Family Interview: A Multi-Center Study

Project Description
The Hi-Fi was originally developed to meet the need for an interview that would comprehensively gather information about the specific issues relevant to TBI that would be useful to the clinician in an applied setting. The new version includes new sections on friendship and intimacy as well as on demographic and pre-injury data.
New York University Medical Center  
NYU Research & Training Center for Head Trauma and Stroke  

Center Publications:

1. Kay, T., Cavallo, M., & Ezrachi, O. The New York University head injury family interview. New York: New York University Medical Center, Research and Training Center on Head Trauma and Stroke.


Center Description

Project Name
Foster Parent Training

Project Description
The assessment instruments have been developed for use with parents to assist them when they go to IEPS or for transition planning for work.
Oregon State System of Higher Education

Publications:


Center Publications:

1. Teaching Research Publications Catalog


Early Childhood Special Education

School of Education & Human Development

State University of New York-Binghampton
Binghamton, NY 13901
(607) 777-2727

Project Director: Christine Salisbury, Ph.D.
Research Director:

Funding Agency:
Funding Period:

No description included.

Center Description

No projects listed.
State University of New York at Binghamton

Publications:


5. Salisbury, C. (no date). Parenthood and the need for respite. (pp. 3-28).


Center Publications:

Project Name
The Usefulness & Validity of the HOME Inventory as Applied to Families with Disabled Members

Project Description
This project reports on psychometric and descriptive information about the use of the HOME Inventory when administered to families having children with disabilities.
Center for Research on Teaching & Learning

Center Publications:

Project Name
Parent Training: Media-Based Versus Professionally Led Training

Project Description
Sixty-five families were randomly assigned to media-based training, the same curriculum with a professional leader, or a delayed-training control condition. Media-based programs may be a cost-effective way to make parent training more widely available.
Publications:


Project Name
The impact of intensive behavioral intervention on families of preschool-aged artistic children.

Project Description
The intervention consists of approximately 40 hours per week of in-home one-to-one treatment for one to three years.

Project Name
Intensive Behavioral Treatment for Young Developmentally Delayed Children

Project Description
This investigation is intended to enhance intellectual, educational and social skills of young developmentally delayed children so they can take better advantage of the educational opportunities provided for them in the public schools.
UCLA Clinic for the Behavioral Treatment of Children

Center Publications:

No publications were directly provided to the Beach Center.
Project Name
Study in Progress

Project Description
The purpose of this study was twofold: to extend research on stress in parents of children with autism and to compare the results of this research with established normative data.
Publications:


Center Publications:

Project Name
The Development and Evaluation of an Intervention Program for Families with Learning Disabled Youth

Project Description
The goal of this project is to develop and evaluate a program for families with children with learning disabilities by identifying family needs and the development of program materials and instructional procedures to address these needs.
Institute for Research in Learning Disabilities

Center Publication:

Center Description
See project description. (Some research done with Dr. Melly Reid at the University of Washington.)

Project Name
My Family and Friends: 6 to 12 Year Old Children's Perceptions of Social Support

Project Description
This was an evaluation of the instrument, 'My Family and Friends,' used to study children's subjective impressions about social support.
Publications:


Center Publications:

1. Child Instruments
   - My Family and Friends, Part 1
   - My Family and Friends, Part 2
   - What I’m Like and What I Think About Others in the Family
   - What is Important in My Family
   - Ways to Get Chores Done in My Family
   - Ways My Family Helps Me with School
   - Young Person’s Opinion of Family Size and Education

2. Adult Instruments
   - Assessment and Description of Family Life
   - Assessment of Parenting Skills
   - Assessment of Individual Family Members and Relationship Within the Family
   - Tools to Assess Parents’ Personality, Mood, & Health
Center Description

See project description.

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Project Name
Parents' Graduation Alliance

Project Description
This project provides support to families of students with severe disabilities as they face the transition from school to work and adult life.

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Project Name
Parent/Professional Graduation Alliance

Project Description
This project, built on the previous project, provides support and training to families whose deaf-blind children are leaving school and going to adult life.
Specialized Training Program

Publications:


Center Publications:

1. Family Transition Planning and Support System

2. Human Subjects Activity Review Form

3. Parents Graduation Alliance: Transition Support for Severely Handicapped Students

Project Name
Assessment and Treatment of Abuse and Neglect in Handicapped Children and Adolescents

Project Description
This project will examine the incidence of abuse and neglect in 150 consecutive admissions of children with multiple disabilities hospitalized for psychiatric reasons. The project will then apply comprehensive behavioral treatment to 10 parents who have physically abused their children and 10 parents who have neglected their children.

Project Name
Dyadic Interactions in Parents of Visually Handicapped Adolescents: A Sequential Analysis

Project Description
This study contrasted the interaction patterns and psychological adjustment of 25 parents of adolescents with visual impairment with 25 parents of adolescents with spina bifida and 25 parents of adolescents without disabilities.
University of Pittsburgh

Publications:


Center Publications:


Center Description
See project description.

Project Name
Financing Home Care for Children with Chronic Illness & Severe Disabilities

Project Description
The purpose of this grant was to examine financing models for supporting children with severe disabilities and chronic illness so that they can live at home. One product is a technical assistance manual.

Project Name
Becoming Informed Consumers: A National Survey of Parents's Experience with Respite Services

Project Description
This project involved three major activities: establishment and utilization of a national advisory panel, an indepth review of literature on family supports, system change, and consumer empowerment as it relates to respite services, and national survey of parents.
Center Publications:


Project Name
Model Family-Professional Partnership Interventions for Childhood Traumatic Brain Injury Survivors

Project Description
This project deals with the social, psychological and economic impact of traumatic brain injury on families of children up to 16, with the goal of designing valid collaborative interventions for professionals and families at the critical stage of the restorative process.
New York State Head Injury Association

Center Publications:

1. Model Family-Professional Partnership Interventions For Childhood Traumatic Brain Injury Survivors- Abstract.
Project Name
Discover the Possibilities: Integration Curriculum for Parents

Project Description
Through this project, PEAK will utilize the parents training parents model to develop and pilot a curriculum in workshop format. It will then be distributed by parent training and information centers to other parent groups who wish to offer it to families in their state or area.

Project Name
Parents and Integration: Reclaiming the Vision

Project Description
The intended outcome of this project is that parents whose children receive special education services will be enabled to reclaim their visions for their children and will have resources to advocate for their sons and daughters to be more fully integrated in school and community life.
PEAK Parent Center, Inc.

Center Publications:

1. Brochure, Master New Possibilities: Peak Integration Project
2. Brochure, PEAK
4. SPEAK OUT (newsletter, 3 times annually)
5. SPEAK OUT Reprint Series
   Finding the doctor who is right for you
   Getting Help when you need it-Counseling
   Will Your Child Be Putting on a Cap & Gown?
   Watch Your Language
   Meeting Children’s Unique Needs: Teachers Who Do It
   How Can Parents Be Good Partners?
   Now Possibilities emerge for Special Education
   A Powered Wheelchair for your child?
   Getting Ready to Go for a staffing
   Seizures in Children
   Selecting a Private PT or OT
   Whys and Hows of choosing a Preschool

6. Starting a Parent Support Group
7. Switchback: Looking Ahead & Looking Back
8. Integration
9. PEAK calendar, 3/89
Project Name
Fathers Present/Fathers Absent Project

Project Description
This study compared the extent to which the presence of a young male child with or without developmental disabilities affected adaptation and family roles for both mothers and fathers.

Project Name
Mothers of Children with Autism or Communication Disorders

Project Description
This study demonstrates the effectiveness of a modified Double ABCX model in predicting successful adaptation in 45 families of children with autism and communication disorders.
TEACCH Program

Publications:


Center Publications:

1. Publications list
Through the Looking Glass

801 Peralta Avenue
Berkeley, CA 94707
(415) 525-8138

Project Director: Megan Kirshbaum, Ph.D.
Research Director:

Funding Agency: NIDRR, and Easter Seal Research Foundation 1985-88
Funding Period: 1985-88

Center Description
'Through the Looking Glass' orientation is to formulate research questions and priorities as an outgrowth of longterm clinical experience with families with disability issues, and based on the personal/family experience of its dual peer/professional staff and clientele. Emphasis is on parents with disabilities, and they have worked with more than 125 families with at least one parent with a disability.

Project Name
Bridges

Project Description
The purpose was to develop a service model for parents with disabilities.

Project Name
Through the Looking Glass

Project Description
This project resulted in the development of a training package for professionals concerning families and babies with disability issues in EITHER baby or parent.

Project Name
Through the Looking Glass

Project Description
This project focused on demonstrating via videotape how experienced parents with disabilities could teach expectant or new parents various techniques, adaptive strategies or equipment modifications.
Through the Looking Glass

Publications:


Center Publications:

1. Parenting with a Disability, biannual newsletter
FEEDBACK

WE WOULD LIKE TO HEAR FROM YOU.

CENTER (OR PROJECT) TITLE -

ADDRESS -

CITY, STATE, ZIP -

PHONE - (  )

DID THIS BOOKLET DESCRIBE YOUR CENTER OR PROJECT(S) CORRECTLY?

IF NOT, WHAT IS THE DESCRIPTION YOU PREFER?

WERE THE PUBLICATIONS YOU MAILED US LISTED CORRECTLY?

IF NOT, WHAT IS THE CORRECT LISTING?

WAS THE INFORMATION IN THIS BOOKLET USEFUL TO YOU?

WHAT WOULD YOU LIKE TO SEE INCLUDED IN FUTURE BOOKLETS?

ATTACH ADDITIONAL SHEETS FOR INFORMATION THAT DOES NOT FIT ON THIS PAGE.

Thank you for your feedback.

Beach Center on Families and Disability
Bureau of Child Research
The University of Kansas
4138 Haworth
Lawrence, KS 66045
73