



Welcome to the RRTC on Community Integration of Persons with TBI

Welcome to the first newsletter for the Rehabilitation Research and Training Center (RRTC) on Community Integration of Persons With Traumatic Brain Injury (TBI). Researchers at The Institute for Rehabilitation and Research (TIRR) and Baylor College of Medicine were awarded the RRTC grant by the National Institute on Disability and Rehabilitation Research (NIDRR) on November 1, 2003. This first newsletter is to help make you aware of the mission and goals of our Center, including all of the research and training projects that we will conduct over the next 5 years. We will publish 2 newsletters each year to give you updates on our projects and to tell you what we find out that can be useful to persons with TBI, their family members, and professionals involved in treating or advocating for persons with TBI. We look forward to working with the larger TBI and disability communities and invite feedback and collaboration (see the back page for information on how to contact us).

OUR MISSION

- That all those affected by TBI, including traditionally under-served populations, have access to information, resources, and services that maximize participation in their communities and that treating professionals have the necessary information to meet the needs of persons with TBI
- That all areas of community integration, including traditionally under-emphasized areas such as friendship, intimacy, and creative expression, be addressed
- That attitudinal barriers to community integration of persons with TBI be reduced
- That new types of partnerships, such as those with the larger disability community, be established in order to empower persons with TBI to have a voice in creating community services and networks to facilitate maximal community participation.

OUR GOALS INCLUDE

- Assessing and identifying community integration needs from traditionally under-served populations,

including members of racial/ethnic minority groups, individuals from rural communities, and those with mild TBI

- Understanding environmental factors that either serve to better or worsen community participation for individuals with TBI
- Focusing on increasing the number and quality of social relationships for individuals with TBI, by developing and implementing new and innovative networking systems
- Decreasing attitudinal barriers to community integration by increasing community awareness of the impact of brain injury, dispelling myths about TBI, and increasing positive attitudes about individuals with brain injury in the community
- Providing a bridge from rehabilitation into the community by educating and training paraprofessionals, healthcare professionals, and peers in how to meet the needs of persons with TBI
- Including individuals with TBI and family members or friends of those individuals in all aspects of research, training, and education
- Creating sustainable, community-based programs for those affected by TBI through working with community organizations. ■



Pictured left to right are Co-Principal Investigators Angelle Sander, PhD, Margaret Struchen, PhD and Director of Training, Karen Hart, PhD. See story on page 2.

INTRODUCING THE CENTER DIRECTORS AND INVESTIGATORS

Co-Principal Investigator: Angelle M. Sander, Ph.D., is Assistant Professor of Physical Medicine and Rehabilitation in the Department of Physical Medicine and Rehabilitation at Baylor College of Medicine and is the Residency Research Director for the Department. She is Associate Director of TIRR's Brain Injury Research Center. She is also the Neuropsychologist for the inpatient rehabilitation unit at Quentin Mease Community Hospital, in the Harris County Hospital District. She was awarded a Mary E. Switzer Rehabilitation Research Fellowship from the National Institute on Disability and Rehabilitation Research (NIDRR) and has been Principal Investigator on grants from NIDRR and the National Academy of Neuropsychology. In addition to the RRTC, she is currently Principal Investigator on an NIH/NCMRR pilot study investigating predictors of health care utilization in minority stroke patients. Research interests include efficacy of rehabilitation interventions, family adjustment to TBI, environmental factors impacting outcome, and impact of injury on persons from diverse backgrounds.

Co-Principal Investigator: Margaret A. Struchen, Ph.D., is Assistant Professor in the Department of Physical Medicine and Rehabilitation at Baylor College of Medicine and Neuropsychologist at the Brain Injury Research Center of TIRR. Her research interests include assessment and treatment of social skills impairments following traumatic brain injury, understanding efficacy of rehabilitation interventions, and outcome measurement following acquired brain injury. Dr. Struchen is currently Principal Investigator for a NIDRR funded Field-Initiated grant on Assessment

of Social Communication Abilities following Traumatic Brain Injury and Co-Investigator for the NIDRR-funded Rehabilitation Research and Training Center (RRTC) on Rehabilitation Interventions Following TBI. Dr. Struchen also serves as President-Elect for the Board of Directors of the Brain Injury Association of Texas and as Vice-President of the Board of Directors for the Texas Brain Injury Network of Houston.

Director of Training: Karen A. Hart, Ph.D., is a tenured Associate Professor in the Department of Physical Medicine and Rehabilitation (PM&R) and Vice President for Education at TIRR. Dr. Hart is also Director of Education for the Departments of PM&R at Baylor College of Medicine and the University of Texas-Houston Medical School and in that capacity oversees the residency and fellowship training programs for the largest PM&R residency program in the United States. She has been Director of Training for four NIDRR-funded RRTC's during the past 19 years (RRTC for Community-Oriented Services for Persons with Spinal Cord Injury (SCI), RRTC on Community Integration of Individuals with SCI, RRTC on Rehabilitation Interventions Following TBI, and RRTC on Community Integration in Persons with TBI). She served as the Center Co-Director for the RRTC for Community Integration of Individuals with SCI and is currently the Project Director for the NIDRR Model SCI Systems Dissemination Center. Dr. Hart is a past President of the National Association of Rehabilitation Research and Training Centers, is a past President of the American Congress of Rehabilitation Medicine, and is a Board Member

of the American Spinal Injury Association. Dr. Hart oversees the day-to-day operation of the training projects.

Medical Director: Sunil Kothari, M.D., is a board-certified physiatrist and Attending Physiatrist for the Brain Injury and Stroke Program at TIRR. Dr. Kothari is an Assistant Professor in the Department of Physical Medicine and Rehabilitation for Baylor College of Medicine and Adjunct Assistant Professor in the Department of Physical Medicine and Rehabilitation at the University of Texas School of Medicine-Houston. Dr. Kothari completed his residency at the Rehabilitation Institute of Chicago, where he served as Chief Resident. He completed a Fellowship in Brain Injury at TIRR and joined as Attending Physiatrist in 2000. Dr. Kothari has research interests in the area of traumatic brain injury and quality of life. He was voted Teacher of the Year 2000 for the Department of Physical Medicine and Rehabilitation at Baylor College of Medicine and received the R. Edward Carter, Jr., M.D Award for Continuing Contributions and Accomplishments for the BCM/UT PM&R Alliance. He was recently honored as the 2003 Texas Rehabilitation Association Physician of the Year.

Co-Investigators:

Jerome S. Caroselli, Ph.D., Lisa Keenan, Ph.D., Carol Gill, Ph.D., Sharon A. Brown, Ph.D., Dan Graves, Ph.D., Nina Robins, M.A., H. Julia Hannay, Ph.D., Timothy Atchison, Ph.D., Mark Sherry, Ph.D., John Corrigan, Ph.D., Jennifer Bogner, Ph.D., Faye Chiou-Tan, M.D., Les Young, Claudia Roberston, M.D., Monica Rosel, RN, BSN ■

OUR RESEARCH PROJECTS

1 INCREASING SOCIAL NETWORKING OPPORTUNITIES FOLLOWING TBI

Principal Investigator: Margaret A. Struchen, Ph.D., Co-Principal Investigator: Sunil Kothari, M.D.

This study is a randomized controlled clinical trial of a peer mentoring program focused on increasing social interaction opportunities following TBI. Persons with TBI who have been successful in social integration after their injuries will be paired to those with TBI who are reporting not being happy with their level of social activity. Social activity levels will be compared between persons receiving peer mentoring to those of persons on the waiting list for participating in the peer mentoring. This study will be conducted along with the Transitional Learning Center in Galveston.

2 ETHNIC DIVERSITY IN ACCEPTANCE OF DISABILITY, COMMUNITY INTEGRATION NEEDS, BARRIERS, AND SUPPORTS

Principal Investigator: Angelle M. Sander, Ph.D.

The purpose of this study is to find out whether there are differences between racial/ethnic groups in regard to acceptance of disability, perceived importance of different areas of community integration, and in perceived attitudinal barriers and supports for community integration. Understanding these factors can lead to development of services that are tailored to the needs of persons from diverse ethnic groups.

3 FAMILY MEMBERS AS REHABILITATION PARAPROFESSIONALS: USE OF DISTANCE LEARNING AS A TRAINING TOOL FOR FAMILY MEMBERS IN RURAL AREAS

Principal Investigator: Angelle M. Sander, Ph.D.

This study will be conducted with West Texas A&M University. The project will develop and evaluate a distance learning program to train family members of persons with TBI to implement cognitive rehabilitation strategies and environmental changes to improve the functioning of the person with TBI in the home setting. The population served by this project will include persons in rural West Texas and the bordering regions of Oklahoma, Colorado, and New Mexico. This is an under-served population, with no access to comprehensive inpatient or outpatient rehabilitation services.

4 EVALUATING AND CHANGING EMPLOYERS' ATTITUDES TOWARDS PERSONS WITH TBI

Principal Investigator: Walter M. High, Jr., Ph.D.

This study will partner with the Department of Assistive and Rehabilitative Services and the Transitional Learning Center in Galveston. The study will involve assessment of employers' knowledge regarding TBI, their attitudes toward persons with TBI, and the relationship of these attitudes and knowledge to maintenance of employment in persons with TBI. The final year of funding will be devoted to piloting an educational intervention aimed at changing knowledge and attitudes of employers.

5 EFFECTIVENESS OF A BRIEF EDUCATIONAL INTERVENTION FOR REDUCING SUBSTANCE ABUSE AFTER TBI

Co-Principal Investigators: Angelle M. Sander, Ph.D. & John Corrigan, Ph.D.

This study will be conducted at 2 sites: the Harris County Hospital District in Houston and Grant Hospital affiliated with Ohio State University. The project is a randomized clinical trial to determine the effectiveness of a brief educational intervention for decreasing positive expectations regarding the effects of alcohol use, increasing readiness to change, and decreasing actual use of alcohol and drugs in persons with TBI who have an at-risk substance abuse history.

6 EXPLORING INTIMACY FOLLOWING TBI

Principal Investigator: Carol Gill, Ph.D., Co-Principal Investigator: Sunil Kothari, M.D.

This study is designed to explore how the experience of TBI affects feelings of intimacy and self-identity as a sexual or intimate partner for both persons with injury and their intimate partners. Intimate relationships are an important aspect of quality of life, and little has been studied about intimacy following TBI. This study will be conducted at two sites: the University of Illinois – Chicago and TIRR in Houston.

7 UNDERSTANDING FACTORS THAT CONTRIBUTE TO DECREASED SOCIAL INTEGRATION FOR PERSONS WITH TBI

Principal Investigator: Margaret A. Struchen, Ph.D.

This project explores the impact of environmental factors and social communication abilities on social integration and emotional functioning following TBI. The study will involve persons from traditionally under-served populations and will be conducted within the Harris County Hospital District. Understanding the relationships between these factors will contribute to recommendations for interventions that can improve social functioning after TBI.

OUR TRAINING PROJECTS

1 NATIONAL INFORMATION, EDUCATIONAL RESOURCES, DISSEMINATION AND TECHNICAL ASSISTANCE CENTER FOR THE COMMUNITY INTEGRATION OF INDIVIDUALS WITH TRAUMATIC BRAIN INJURY

Project Director: Karen A. Hart, Ph.D.

This project will serve as a centralized resource for information on community integration following traumatic brain injury. This project is designed to meet the needs of people with TBI and their families as well as researchers, students, educators and policymakers. Activities include:

- Website: www.tbicommunity.org
- Database of educational resources available nationally
- National Information, Dissemination, and Technical Assistance Center
- Newsletter: "TBI Community News"

2 INCREASING COMMUNITY AWARENESS OF TBI AND REDUCING ATTITUDINAL BARRIERS

Project Director: Karen A. Hart, Ph.D.

Lack of understanding about TBI among family, friends, neighbors, co-workers, and the like can lead to attitudinal barriers that limit a person with TBI from participating in their community. This project is designed to develop educational materials in English and Spanish that can be used by persons with TBI to inform persons within their community about brain injury. The materials will be developed with the Brain Injury Association of America, Inc., using input from consumers. Activities include:

- Fact sheets
- Videotaped educational materials
- Booklets on issues related to community integration following TBI

3 SOCIAL ACTION NETWORKING IN PERSONS WITH TBI

Project Director: Carol Gill, Ph.D., Co-Project Director: Sunil Kothari, M.D.

The purpose of this project is to begin a social action networking model that has been successful for increasing positive self-identity, social connection, empowerment, and hope in persons with disability. The project will be carried out along with Dr. Gill and colleagues at the University of Illinois-Chicago. The project will involve conducting several groups for persons with TBI in the Houston-Galveston and Austin areas.

4 CENTER FOR CREATIVE EXPRESSION FOR PERSONS WITH TBI

Project Director: Karen A. Hart, Ph.D.

This project will partner with The Orange Show Foundation, a local organization for artists, whose mission is to promote the artistic expression of ordinary people. The project will bring together artists (musicians, painters, sculptors, theater performers, dancers, etc.) and individuals with TBI at organized classes twice a month in a variety of media. The artists leading the classes will be aided by physical, occupational, speech, and music therapists with a specialization in TBI. The project is aimed at helping persons with TBI find meaning through self-expression.

5 TRAINING OF HEALTHCARE PROFESSIONALS IN THE COMMUNITY INTEGRATION NEEDS OF PERSONS WITH TBI

Project Director: Margaret A. Struchen, Ph.D.

Many individuals with TBI will be receiving their primary medical services, behavioral healthcare services, and case management services from non-specialist professionals. Family practice physicians, internists, psychologists, counselors, and social workers who may be unfamiliar with TBI may become the primary service provider, particularly as the time since injury increases. This project is designed to develop educational materials for non-specialist healthcare professionals about the community integration needs of persons with TBI.

6 REHABILITATION RESEARCH FELLOWSHIPS

Co-Project Directors: Margaret A. Struchen, Ph.D., Angelle M. Sander, Ph.D.

The aim of this Fellowship is to provide cross-training in rehabilitation research with individuals with TBI for psychologists with backgrounds in neuropsychology or rehabilitation psychology so that graduating Fellows will have an understanding and skills in these fields.

7 STATE-OF-THE-SCIENCE CONFERENCE ON COMMUNITY INTEGRATION FOR PERSONS WITH TBI

Project Director: Karen A. Hart, Ph.D.

The intent of this project is to bring together scientists involved in community integration of persons with TBI and appropriate constituents to dialogue about the state-of-the-science, to identify gaps in knowledge and to recommend future research priorities. This will take place in Houston, TX during the latter part of year three of the Center's operation.

Collaborating Institutions and Agencies

Ohio State University and its affiliate, Grant Hospital- St. Joseph's Medical Center, will be a collaborating site on our substance abuse intervention project.

DRS. JOHN CORRIGAN and **JENNIFER BOGNER,** will be co-investigators on the grant. Both Dr. Corrigan and Dr. Bogner are tenured faculty in the Department of Physical Medicine and Rehabilitation at Ohio State University. Dr. Corrigan and Dr. Bogner are national leaders in conducting research on the assessment and treatment of substance abuse after TBI. They have created an educational video on the impact of substance abuse for persons with TBI. This video will be used in our intervention study and will be translated into Spanish.

DR. TIMOTHY ATCHISON is Assistant Professor in the Department of Psychology at **West Texas A&M University** in Canyon, Texas. Dr. Atchison and



Drs. John Corrigan and Jennifer Bogner

staff at West Texas A&M's teleconferencing center will be partnering with us on our research project aimed at training family members in rural areas to conduct cognitive rehabilitation strategies in the home. Participants for this project will be recruited from **Northwest Texas Hospital (NTH)** in Amarillo, Texas. NTH is a Level III trauma center that serves the top 23 counties of the Texas panhandle.

DR. CAROL GILL is Associate Professor of Human Development, Department of Disability and Human Development, at the **University of Illinois – Chicago.** Dr. Gill and **MS. NINA ROBINS** will be partnering with us on a research project aimed at understanding intimacy issues following TBI. Participants for this study will be recruited within the Chicago and Houston areas. Dr. Gill and **DR. MARK SHERRY** will

also be working with the Center on a training project that will attempt to broaden the social action networking training program that has been successful in the Chicago area to persons with TBI living in the Houston-Galveston and Austin areas. The **Houston Center for Independent Living (HCIL)** will be working with us for the Social Action Networking project in the Houston area.

Three of the Center's research projects involve collaboration with investigators from the **Harris County Hospital District.** **DR. CLAUDIA ROBERTSON,** Department of Neurosurgery, and **DR. FAYE CHIOU-TAN,** Department of Physical Medicine and Rehabilitation, will work with us on a project looking into ethnic differences in acceptance of disability and community integration needs following TBI, on a project looking at factors that relate to social integration after TBI, and on a clinical trial to investigate the effectiveness of an intervention to address substance abuse in persons with TBI.

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Tim Atchison, Ph.D. and Able Soto



Ms. Nina Robins and Drs. Carol Gill and Mark Sherry

Collaborating Institutions and Agencies

(Continued from page 5)

The Orange Show Foundation, an organization of artists, writers, musicians, and other creative professionals will be partnering with us on the Center for Creative Expression for Persons with TBI. The Orange Show will provide the artist instructors and materials for all courses offered through our Center for Creative Expression.

The Metropolitan Multi-Service Center will serve as the location of the visual and performing arts courses for the Center for Creative Expression for Persons with TBI. It is a fully accessible facility conveniently located within the city of Houston, TX.

The Brain Injury Association of America, Inc. (BIAA), will be working with us on projects involving building community awareness of traumatic brain injury. In addition, we will be working with BIAA to obtain feedback from consumers across the nation on our projects and educational materials. We will also be linking our website to the BIAA website to help give out educational materials produced through our Center. **The Brain Injury Association of Texas (BIATX)** will also be working with us to look at materials, to carry on projects after the time period of the grant, and to help hand out materials within Texas.

The Transitional Learning Center in Galveston will be working with us on two research projects. **DR. JEROME CAROSELLI** and **DR. LISA KEENAN** will be working on the social peer-mentoring project and on a project designed to assess the attitudes of employers about hiring individuals with TBI. **MR. LES YOUNG**, Program Specialist for Neurological Disorders from the **Department of Assistive and Rehabilitative Services (DARS)**, will also be working with us on the project involving assessment of employers' attitudes. ■

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