Early Onset Dementia Information and Thoughts

John Keegan, Ph.D. CRC, Hunter College, CUNY, New York, USA
January 9, 2015, University of Tsukuba, JAPAN

Top Resources:

Alzheimer's Association- www.alz.org

-NYC chapter is thought to be more progressive and offers more- for example, the run support groups in addition to training people to run groups like most chapters

Alzheimer's Foundation of America- www.alzfdn.org

-this is a membership organization (have to join and pay dues) that provides training for members to become a Qualified Dementia Training Professional (QDTP)- this person will provide services training for home health aides and early stage support groups for caregivers

National Adult Day Services Association- www.nadsa.org

-public policy work

New York Office for the Aging (NYSOFA)- www.aging.ny.gov

-look at the guidelines for services they developed

Day Care:

Social Model Daycare vs. Medical Model Daycare

Social Model Daycare

-for people with dementia and frail elderly

-for people who can't attend senior centers due to one or more functional limitations

-include a range of services including case management, support groups, bathing, etc.

-more flexible and individualized than medical model daycare

-ranges from $10-18 per hour, with more expensive programs having a wider range of services

-clients are often resistant to attending and one program director said they often tell (mislead) client by saying that they are going to volunteer and then attend without reservations

Challenges:

-hard to get dementia diagnosis under 65

-Medicare (health care for people 65 and over, though PWDs can qualify)

-often need private pay until someone can qualify for Medicare

Research on dementia:

-Appears to be more focused on caregivers for people with dementia than for people with dementia

My thought: PWDs take a back seat, as it appears interventions for the cognitively well seen as more important. There are often negative attitudes at play when it comes to disabilities, but maybe more for dementia (How many other disabilities have more research done on interventions for the caregivers, than for people with the disability itself?)
Mittelman & colleagues (NYU)- has done a good deal of research mostly focused on caregivers:
(NYU study on caregivers began in 1980s and didn't include any interventions for people with dementia.)

Gaughler, Reese, and Mittelman (2013)
Purpose: This study determined whether the NYU Caregiver Intervention, adapted in Minnesota for adult child caregivers (NYUCI-AC), prevented or delayed residential care placement for persons with dementia. Design and Methods: A single-blinded randomized controlled trial design was used. One hundred and seven adult child caregivers of persons with dementia were randomly assigned to the NYUCI-AC treatment group who received individual and family counseling, support group referral, and ad hoc consultation or a contact control group. Participants were asked to complete structured assessments quarterly during Year 1 and every 6 months thereafter for a minimum of 2 years. Results: Two thirds (66%) of adult child caregivers in the control condition admitted their parent to a residential care setting compared with 37% in the treatment condition. Logistic regression and Cox proportional hazards models found that NYUCI-AC participants were significantly less likely ($p < .05$) to admit their parents to a residential care setting and delayed their parents' time to admission significantly longer (228.36 days longer on average) than those in the control group. Implications: The multicomponent NYUCI-AC offered adult children the psychosocial support required to continue providing care to cognitively impaired parents at home.
Take away: Supportive mental health interventions for caregivers delay admission to residential care settings for two-thirds of a year.

Mittelman (2008): There has been a focus in the research on caregivers, but often based on false premise that caregiving is a disorder like (or always causing) depression.
Challenges with measurement and inconsistent findings, finding differences in Latino, Caucasian, and African American caregivers.
NYU study on caregivers began in 1980s and didn't include any interventions for people with dementia.
Small non-randomized studies suggest that psychosocial interventions, such as physical fitness training, activities therapy and nutritional interventions and complementary therapies, such as acupuncture and massage, may be effective in enhancing strengths and improving many aspects of patient and caregiver well-being, including mood and social support; however, the evidence is mostly anecdotal.>>> Large-scale studies to evaluate the potential effectiveness of interventions to increase the wellbeing of people with dementia are essential.

Experience at UW where one of my professors was also running a program for physicians who had their medical licenses suspended, but found that many were related to the onset of dementia and were looking to add a dementia screening at the beginning or prior to beginning the training which was 2-3 weeks long and quite expensive for the physicians.

若年性認知症・高次脳機能障害就労支援
国際研究ネットワーク会議

Work Support for Early Onset Dementia and TBI
International Research Network Meeting

研究ネットワーク会議のご案内(FD研修兼)

Dr. John Keegan, Ph.D., CRC, Hunter College, CUNY, New York, USA
Dr. Sandra Fitzgerald, Ph.D. CRC, San Francisco State University, CA, USA
Dr. Mayu Fujikawa, Ph.D. CRC, Tohoku University, JAPAN

日時:　平成27年1月11日(日)12:00-16:00
場所:　筑波大学文京校舎 120教室(or 430ラウンジ)
(東京都文京区大塚3-29-1)

厚生労働省
Ministry of Health, Labour and Welfare

H26年度厚生労働省科学研究　若年性認知症と高次脳機能障害者の社会保障のあり方に関する調査研究
(H26－政策－一般－009)

FACILITATING VOCATIONAL RECOVERY FOR PERSONS LIVING WITH TRAUMATIC BRAIN INJURY

SANDRA FITZGERALD, PHD, CRC
SAN FRANCISCO STATE UNIVERSITY
INVITED PRESENTATION AT UNIVERSITY OF TSUKUBA
JANUARY 9TH, 2015

Go Giants!!

OUTLINE

Brief overview of TBI & diagnosis

Functional impact of TBI on employment

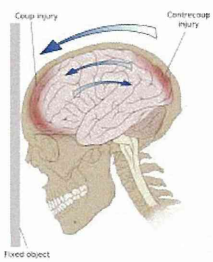
Vocational rehabilitation process for TBI

- Public VR and supported employment

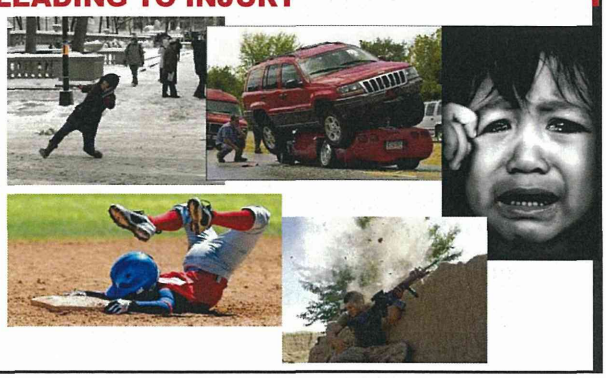
Vocational recovery and psychosocial benefits of employment

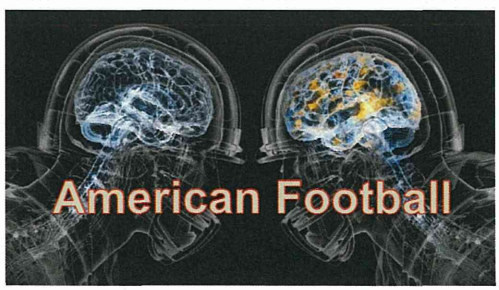
My own research interest in vocational recovery for persons living with severe mental illness

TYPE OF BRAIN INJURY



MOST COMMON EVENTS LEADING TO INJURY





REALLY BAD FOR THE BRAIN!!

DIAGNOSIS OF TBI

Glasgow Coma Scale (GCS):

- Measure functioning related to speech, eye opening abilities, and movement
- Rated on person's responses in 3 areas and calculate a total score

Mild TBI:

- Person not unconscious or unconscious less than 30 minutes
- Memory loss lasting less than 24 hours
- GCS score from 13 to 15.

(Chan, Leahy, Saunders, 2005)

DIAGNOSIS OF TBI

Moderate TBI:

- Person unconscious for more than 30 mintues and up to 24 hours
- Memory loss lasted anywhere from 24 hours to 7 days
- GCS was 9 to 12

Severe TBI:

- Person unconscious for more than 24 hours
- Memory loss lasted more than 7 days
- GCS was 8 or less

(Chan, Leahy, Saunders, 2005)

OTHER DIAGNOSTIC TOOLS

Cognition tests

Neuropsychological Assessments

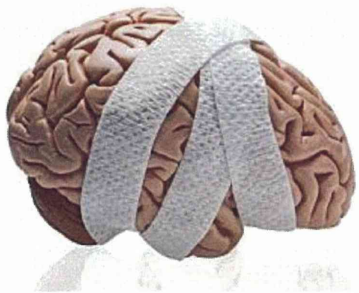
Imaging Tests

- Computerized tomography (CT)
- Magnetic resonance imaging (MRI)
- Intracranial pressure (ICP) monitoring

Screening for veterans/service members:

http://dvbic.dcoe.mil/diagnosis-assessment/article/concussionmtbi-screening

Functional limitations/impairments



POTENTIAL IMPAIRMENTS

- Cognitive deficits
- Motor deficits
- Perceptual or sensory deficits
- Communication/language
- Social difficulties
- Regulatory disturbances
- Personality or psychiatric changes
- Traumatic epilepsy

(National Institute of Neurological Disorders and Stroke,2014)

COGNITIVE IMPAIRMENTS

- CONFUSION
- SHORTENED ATTENTION SPAN
- MEMORY PROBLEMS OR AMNESIA
- PROBLEM SOLVING DEFICITS
- PROBLEMS WITH JUDGEMENT
- INABILITY TO UNDERSTAND ABSTRACT CONCEPTS
- LOSS OF SENSE OF TIME AND SPACE
- DECREASED AWARENESS OF SELF AND OTHERS
- INABILITY TO ACCEPT MORE THAN ONE OR TWO STEP COMMAND SIMULTANEOUSLY

(National Institute of Neurological Disorders and Stroke, 2014)

MOTOR-RELATED IMPAIRMENTS

- Paralysis or weakness
- Spasticity (tightening or shortening of the muscles)
- Poor balance
- Decreased endurance
- Inability to plan motor movements
- Delays in initiation
- Tremors
- Swallowing issues
- Poor coordination

(National Institute of Neurological Disorders and Stroke, 2014)

REGULATORY DISTURBANCES

- Fatigue
- Changes in sleep patterns and eating patterns
- Dizziness
- Headache
- Loss of bowel and bladder control

(National Institute of Neurological Disorders and Stroke, 2014)

PERCEPTUAL OR SENSORY IMPAIRMENTS

- Changes in hearing, vision, taste, smell, and touch
- Loss of sensation or heightened sensation of body parts
- Left or rights sided neglect
- Difficulty understand where limbs are in relation to the body
- Vision problems including double vision, lack of visual acuity or limited range of vision

(National Institute of Neurological Disorders and Stroke, 2014)

COMMUNICATION OR LANGUAGE RELATED IMPAIRMENTS

- Difficulty speaking and understanding speech (aphasia)
- Difficulty choosing the right words to say (aphasia)
- Difficulty reading (alexia) or writing (agraphia)
- Slow , hesitant speech and decreased vocabulty
- Difficulty forming sentences that make sense
- Problems identifying objects and their function
- Problems with reading, writing, and ability to work with numbers

SOCIAL DIFFICULTIES & PERSONALITY OR PSYCHIATRIC CHALLENGES

- Impaired social capacity resulting in difficult interpersonal relationships
- Difficulty in making and keeping friends
- Difficulty understanding and responding to nuances of social interactions
- Apathy
- Decreased motivation
- Emotional lability
- Anxiety or depression
- Disinhibition (e.g., temper flare-ups, aggression, cursing, low frustration tolerance, inappropriate sexual behavior)

WHICH OF THESE ARE MOST PROBLEMATIC FOR EMPLOYMENT?

Cognitive deficits

Motor deficits

Perceptual or sensory deficits

Communication/language

Social difficulties

Regulatory disturbances

Personality or psychiatric changes

Traumatic epilepsy

(National Institute of Neurological Disorders and Stroke, 2014)

WHY EMPLOYMENT FOR PERSONS WITH TBI?

OBVIOUS: ECONOMIC REASONS

TBI disproportionately affect young people of working age and is the leading cause of disability among people under age 40.

- Unemployment rates range from 55 to 78%, some reports as low as 10 to 34% (depending on whether sheltered workshops, subsidized or unpaid work, volunteer work, homemaker is counted).

Direct medical costs + indirect costs (loss of productivity) =

~$60 billion in costs to US in 2000

(CDC, 2014)

PSYCHOSOCIAL BENEFITS OF EMPLOYMENT (OUTCOMES)

- Leads to higher perceived quality of life
- Increased psychosocial adjustment to their changes in functional capacity
- Decrease in perceived physical ailments
- Reduces economic burden on families
- Increases social interactions and community inclusion
- Reduces risk for depression after TBI

(Seel et al., 2003; Wehman et al., 2003).

INCREASED RISK FOR OTHER HEALTH CONDITIONS

1 to 3 years post injury in relationship to aging and compared to control group with no TBI:

Persons with TBI was:

- 1.8x more likely to report binge drinking
- 11x more likely to develop epilepsy
- 1.5x more increased risk for depression
- 2.3 to 4.5x increased risk for Alzheimer's disease with moderate to severe head injury

(Langlois, Rutland-Brown, & Wald, 2006)

DEPRESSION AND TBI

Studies estimate between 26 to 42% experiencing depression or depressive sx.

Depression exacerbates cognitive impairments and daily functioning

Factors related to depressive symptoms after TBI:

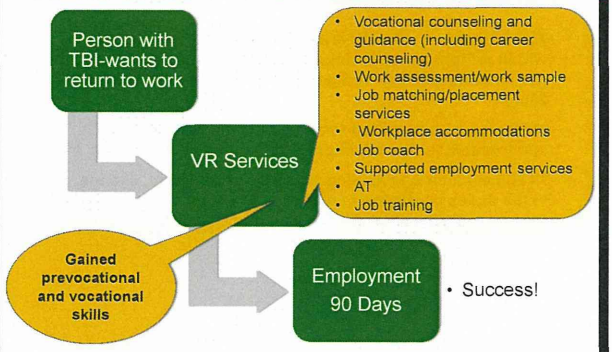
- Unemployment
- Low income
- Minority status

(Seel et al., 2003

VOCATIONAL RECOVERY

EMPLOYMENT HAS A STRONG RELATIONSHIP WITH THE PSYCHOSOCIAL RECOVERY PROCESS FOR PERSONS LIVING WITH TBI

TRADITIONAL VOCATIONAL REHABILITATION SERVICES



VOCATIONAL ASSESSMENT: OBSERVATIONS

- Is there paralysis of other physical problems?
- Is speech affected?
- Does the person present with problems with gait/mobility?
- Does the person appear to have memory problems?
- Is there a problem with social maturity and awkwardness?
- Does the person appear angry, depressed, or anxious?
- Does the person dress and groom appropriately?

(Andrew & Andrew, 2012)

VOCATIONAL ASSESSMENT: INTERVIEW QUESTIONS

Do you experience any physical difficulties (balance, lifting, walking, strength)?

Do you have any difficulties walking on uneven surfaces? Can you walk __km? Can you lift _ kg?

Are you currently in treatment? Who is on your treatment team?

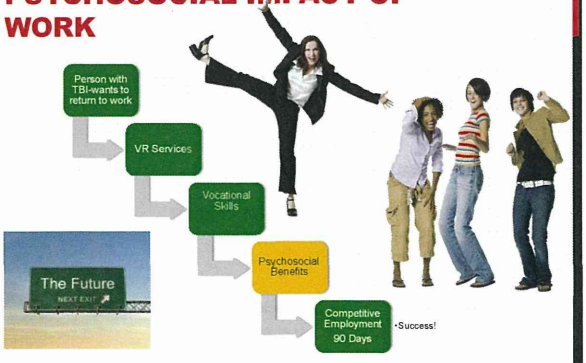
Do you have any problems with daily activities (cooking, cleaning, getting dressed)? Do you have any difficulty handling money?

Do you have any legal issues related to your accident that may interfere with your vocational rehabilitation?

Is your family supportive of you working? What are your expectations and what are theirs?

(Andrew & Andrew, 2012)

WHAT WE OFTEN MISS: PSYCHOSOCIAL IMPACT OF WORK



GETTING TO WORK AFTER TBI VCU WORK SUPPORT: HTTPS://WWW.YOUTUBE.COM/WATCH?V=GQMIL-3LKYI

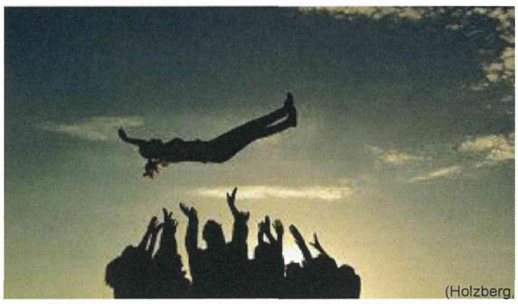
Findings/discussions:

- Early referral and information to VR services
  - Right after medical/psychological stabilization and discharge from hospital
- Have a team or case coordinator for case management services
- Compensatory vs restorative approach (continued cognitive remediation until ready for job placement services).
- Real life evaluations (based on Clubhouse model for 30 days)

SOME ISSUES WITH TRADITIONAL VR SYSTEM

- 75% of persons with TBI return to work lose their job within or right about 90 days without continued supports (National Association of State Head Injury Administrators, 2006)
- Most report help needed to adapt to changes in work environment (or life situation):
- Need help later on adapting to job or life situation, change in job duties or change of manager and job expectations, upward mobility, need or re-examination of job accommodations and strategies.

BEST PRACTICE: SUPPORTED EMPLOYMENT



(Holzberg, 2001),

WHAT IS SUPPORTED EMPLOYMENT?

Essentials:

- Pay for real work (not sheltered employment or subminimum wage work)
- Integration in workplace with nondisabled coworkers
- Long-term ongoing support services
- Interagency cooperation in funding of services

IS SUPPORTED EMPLOYMENT COST EFFECTIVE?: 14 YEAR OUTCOME RESEARCH (WEHMAN ET AL., 2003)

Participated in VCU RRTC Support Employment program 1985-1999

Table 1: Client Characteristics (N=59)

Variable	
Mean age ± SD (y)	32.6±8.4
Range	20–57
Gender (%)	
Male	81.4
Female	19.6
Race (%)	
White	74.6
African American	22.0
Hispanic	3.4
Education (%)	
Less than high school	23.2
High school graduate or equivalent	41.1
Trade or technical school	1.8
Some college	17.9
College graduate	16.1
Unknown (n=3)	
Preinjury work status (%)	
Full-time employment	71.4
Part-time employment	3.6
Student working	1.8
Student not working	12.5
Unemployed not student	10.7
Unknown (n=3)	

Abbreviation: SD, standard deviation.

FINDINGS

Table 2: Lengths of Employment and Client Earnings

Employment Outcomes	
Mean months employed	42.58
Mean monthly earnings ($)	633.63
Mean total earnings ($)	26,129.74
Cumulative months employed	2426
Cumulative earnings ($)	1,489,395

Table 4: Costs of Supported Employment Services

Program Costs	
Mean per person program costs ($)	8614
Mean monthly program costs (per person) ($)	202
Cumulative program costs ($)	491,032

LIMITATIONS/ DISCUSSION

Costs incurred by other rehabilitation professionals not included (e.g., physical therapist, speech therapists) nor costs of assistive devices.

VCU-RRTC program was a well established program-newer SE programs have additional costs related to start up.

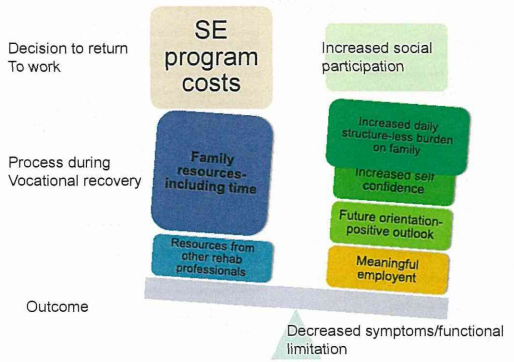
Consider nonmonetary fringe benefits (e.g. medical insurance, SSA benefit reduction)

Important to consider nonmonetary cost benefits:

- **Increased community integration**
- **Improved quality of life**
- **Increased self esteem**
- **Incrased levels of worker integration**

(Wehman et al., 2003)

New cost-benefit analysis



THIS LEADS ME TO MY CURRENT RESEARCH.....

INSTEAD OF TBI-PERSONS LIVING WITH SEVERE MENTAL ILLNESS

HOW DO WE CAPTURE THE OTHER GAINS IN EMPLOYMENT AND SHOW PEOPLE ARE GETTING BETTER OR ENGAGED IN "RECOVERY".

HOW DO WE MEASURE MENTAL HEALTH RECOVERY IN A VOCATIONAL SETTING?

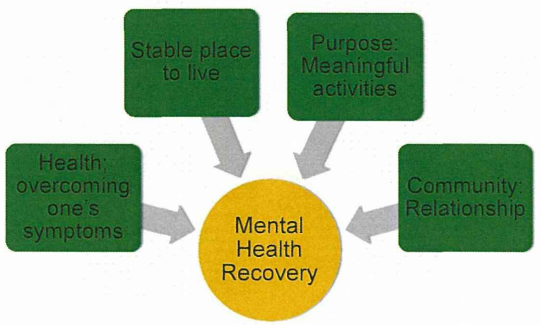
RECOVERY MODEL

Moves away from overreliance on symptom-free criteria as outcome of mental health intervention

Psychosocial functioning becomes more important criterion than the mere absence of symptoms.

Understanding that persons with mental illness can learn to cope and manage symptoms and participate fully in community life.

(Corrigan, Mueser, Bond, Drake, & Solomon, 2008)



(Corrigan, Mueser, Bond, Drake, & Solomon, 2008)

RECOVERY ASSESSMENT SALE (RAS) SCALE

Factor Analysis (Jacobson and Greenly, 2001; Kelly & Gamble, 2005; Onken et al., 2007):

1. personal confidence and hope
2. Willingness to ask for help
3. Goal and success orientation
4. Reliance on others
5. No domination by symptoms

Validated in Japan-good validity and reliability (Cronbach's alpha of 0.89 for entire scale) of Japanese version of 24 item RAS with persons with chronic mental illness living in inpatient ward settings and communities in Japan (Chiba, Miyamoto, & Kawakami, 2009).

VOCATIONAL RECOVERY:

- **How do we define vocational recovery? What are the dimensions, the benchmarks?**
- **How do we measure other psychosocial benefits/factors along with financial gains?**
- **This is my qualitative work in Hawaii**

INDIVIDUAL INTERVIEWS AND FOCUS GROUPS ON MAUI

RESOURCES:
SERVICES FOR BRAIN INJURY

MAIN OFFICE - SAN JOSE

Location: 60 Daggett Drive Phone: (408) 434-2277
San Jose, Ca 95134 Fax: (408) 434-2278

Transportation: Stop at Orchard Station VTA Light Rail

Hours: Monday-Friday 9:00am-5:00pm
Wednesday, Touchstones support group 5:30pm-7:30pm

Email: info@sbicares.org

Website: www.sbicares.org

OAKLAND OFFICE

Location: 1440 Broadway, Suite 200 Phone: (510) 446-7936
Oakland, Ca 94612 Fax: (510) 446-7960

Transportation: Stop at 12th Street Oakland City Center BART Station

Hours: Monday-Friday 9:00am-5:00pm

Email: info@sbicares.org

Website: www.sbicares.org

Mission Statement: To assist people with traumatic brain injury (TBI), acquired brain injury (ABI), and veterans in reaching their highest level of independence through accessible services; family and caregiver support; community awareness; and, prevention of brain injuries.

Services: Rehabilitation Services: clinical support services(speech therapy, occupational therapy, and clinical psychology), cognitive rehabilitation services, independent living skills program, veteran services, and a weekly support group.

Vocational Services: vocational assessments (comprehensive vocational evaluations and situational assessments), immersion services, employment services (employment preparation and job development and placement), and supported employment.

Fees: calculated on a sliding scale depending on ability to pay.

Program information: non-profit organization, Commission on Accreditation of Rehabilitation Facilities (C.A.R.F.) accredited, and recipient of a Certificate of Appreciation for its partnership with the Department of Rehabilitation.

Video about SBI:

https://www.youtube.com/watch?v=OBgRbRP_x5w

SUTTER HEALTH CPMC

Sutter Health CPMC
We Plus You

COMPREHENSIVE INTEGRATED BRAIN INJURY/ SPINAL CORD INJURY PROGRAM

Location: Davies Campus Phone: (415) 600-0200
Castro & Duboce Streets
San Francisco, Ca 94114

Hours: Monday-Friday, 7:00am - 6:00pm

Transportation: about a 10 minute walk from Castro St MUNI Station or about a 4 minute walk from Duboce Ave & Noe St stop

Website: http://www.cpmc.org/services/outpatientrehab/programs/

Program Goal: This program is a coordinated, outcome-driven, integrated rehabilitation program that provides individualized and expert treatment for adult brain injury/ spinal cord injury survivors so that they may achieve greater life satisfaction, independence and productivity. We emphasize a comprehensive and personalized approach to recovery that focuses on the cognitive, emotional, behavioral, social, and physical well being of the individual. Our goal is to achieve functional outcomes focused on home and community integration along with enhancement of self-worth and engagement in productive activities.

Services: Program components: Comprehensive evaluation; coordinated interdisciplinary team; patient and family-centered; individually customized treatment program; weekly interdisciplinary team conferences; group and milieu treatment; and specialized program components include: vocational re-entry, complementary modalities, assistive technology center, peer support program, and individual/group outings.

Brain injury/Spinal cord team includes: board certified physiatrist, certified rehabilitation nurse, physical therapist, occupational therapist, clinical neuropsychologist, speech/language pathologist, recreation therapist, respiratory therapist, case manager, dietician, pharmacist, orthotist, and prosthetist.

Fees: Based on insurance.

Program information: CPRRC is accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF) for Comprehensive Adult Inpatient Rehabilitation Programs, Comprehensive Inpatient Adult Brain Injury Programs, Outpatient Adult Brain Injury Program, the Adult Spinal Cord Rehabilitation System of Care (includes Inpatient and Outpatient services) and Case Management.

REFERENCES

Andrew, J.D. & Andrew, M.J. (Eds.) (2012). *Disability Handbook*. Linn Creek, MO: Aspen Professional Services.

Chan, F., Leahy, M.J., & Saunders, J.L. (Ed.) (2005). *Case management: for rehabilitationhealth professionals* (2nd ed.). Linn Creek, MO: Aspen Professional Services.

Chiba, R., Miyamoto, Y., & Kawakami, N. (2009). Reliability and validity of the Japanese versions of the Recovery Assessment Scale (RAS) for people with chronic illness: Scale development.

Holzberg, E. (2001). The best practice for gaining and maintaining and regainng employment for individuals with traumatic brain injury. *Work: A Journal of Prevention, Assessment and Rehabilitation,* 16(3), 245-258.

REFERENCES

Onken, S., Craigs, C. M., Ridgeway, P., Ralph, R. O., & Cook, J. A. (2007). An analysis of the definitions and elements of recovery: A review of the literature. *Psychiatric Rehabilitation Journal*, 31(1), 9-22.

Wehman, P., Kregel, J., Keyser-Marcus, L., Sherron-Targett, Campbell, L., West, M., & Cifu, D. X. (2003). Supported employment or persons with traumatic brain injury: A preliminary investigation of long-term follow-up costs and program efficiency. *Archive of Physical Medicine & Rehabilitation,* 84, 192-196.

若年性認知症と高次脳機能障害者の
社会保障のあり方に関する調査研究

H26年度厚生労働省科学研究　Ｈ２６－政策－一般－００９
主任研究者　筑波大学　八重田淳

１．若年性認知症就労支援国際研究ネットワーク
日・米・豪・台講演会
Work Support for Early Onset Dementia
International Research Network
Japan, USA, Australia, and Taiwan
日時：　平成27年2月27日（金）12：00–17：00
場所：　筑波大学文京校舎 121教室（or 430ラウンジ）
（東京都文京区大塚3–29–1）

２．高次脳機能障害就労支援国際研究ネットワーク
日・米・豪・台講演会
Work Support for Traumatic Brain Injury
International Research Network Meeting
Japan, USA, Australia, and Taiwan
日時：　平成27年2月28日（土）12：00–16：00
場所：　筑波大学文京校舎 講義室8　（or 430ラウンジ）
（東京都文京区大塚3–29–1）

講師

Dr. Carl Flowers, Rh.D., Southern Illinois University-Carbondale, IL, USA
Dr. Mike Millington, Ph.D. University of Sydney, Australia
Dr. Ming-Hung Wang, Ph.D. National Changhua University of Education, TAIWAN
Dr. Terri Lewis, Ph.D. National Changhua University of Education, TAIWAN

若年性認知症就労支援
国際研究ネットワーク
日・米・豪・台講演会

Work Support for Early Onset Dementia
International Research Network
Japan, USA, Australia, and Taiwan

研究ネットワーク講演会のご案内(FD研修兼)

Dr. Carl Flowers, Rh.D., Southern Illinois University-Carbondale, IL, USA
Dr. Mike Millington, Ph.D. University of Sydney, Australia
Dr. Ming-Hung Wang, Ph.D. National Changhua University of Education, TAIWAN
Dr. Terri Lewis, Ph.D. National Changhua University of Education, TAIWAN

日時:　平成27年2月27日(金)12:00-17:00
場所:　筑波大学文京校舎 121教室(or 430ラウンジ)
(東京都文京区大塚3-29-1)

厚生労働省
Ministry of Health, Labour and Welfare

H26年度厚生労働省科学研究　若年性認知症と高次脳機能障害者の社会保障のあり方に関する調査研究
(H26－政策－一般－009)

高次脳機能障害就労支援
国際研究ネットワーク
日・米・豪・台講演会

Work Support for Traumatic Brain Injury
International Research Network Meeting
Japan, USA, Australia, and Taiwan

研究ネットワーク講演会のご案内(FD研修兼)

Dr. Carl Flowers, Rh.D., Southern Illinois University-Carbondale, IL, USA
Dr. Mike Millington, Ph.D. University of Sydney, Australia
Dr. Ming-Hung Wang, Ph.D. National Changhua University of Education, TAIWAN
Dr. Terri Lewis, Ph.D. National Changhua University of Education, TAIWAN

日時:　平成27年2月28日(土)12:00-16:00
場所:　筑波大学文京校舎 講義室8 (or 430[illegible])
(東京都文京区大塚3-29-1)

厚生労働省
Ministry of Health, Labour and Welfare

H26年度厚生労働省科学研究　若年性認知症と高次脳機能障害者の社会保障のあり方に関する調査研究
(H26－政策－一般－009)

講師紹介

Carl Flowers, Rh.D., CRC, LCPC

Carl Flowers is a Professor and Director of the Rehabilitation Institute at Southern Illinois University Carbondale. He received his doctorate in Rehabilitation from Southern Illinois University in 1993. Dr. Flowers' professional experiences include work as a trainer/provocateur for more than a decade with the Great Lakes and Pacific Northwest Rehabilitation Continuing Education Programs (RCEP). He was the *Lead Specialist* on a multi-year federal grant designed to provide awareness, sensitivity and diversity training for public vocational rehabilitation agencies in Rehabilitation Services Administration (RSA) Region V (with an ultimate goal of increasing equitable services for persons applying and receiving services. Prior to joining the Rehabilitation Institute faculty, he directed the Pacific Northwest Rehabilitation Continuing Education Program (RCEP) (Alaska, Idaho, Oregon and Washington).

Dr. Flowers is a Certified Rehabilitation Counselor (CRC) and a Licensed Clinical Professional Counselor (LCPC). He is a past-president (2007) of the National Rehabilitation Association (NRA) and past Board Chair and President of the National Association of Multicultural Rehabilitation Concerns (NAMRC). Carl was selected a Switzer Scholar in 2001 and was the recipient of the 2012 NAMRC Virgie Winston Lifetime Achievement Award.

Dr. Flowers has published and presented at a number of international and national conferences and served on the editorial board of three professional journals, *Journal of Research, Policy and Education,* Rehabilitation *Counselors and Educators (RCEA) Journal and the Journal of Rehabilitation.* Additionally, he has served as Guest Editor for the *Journal of Rehabilitation Administration* (JRA) and *Psychological Record (PR) and is the Managing Editor (ME) of the Journal of Rehabilitation Administration.*

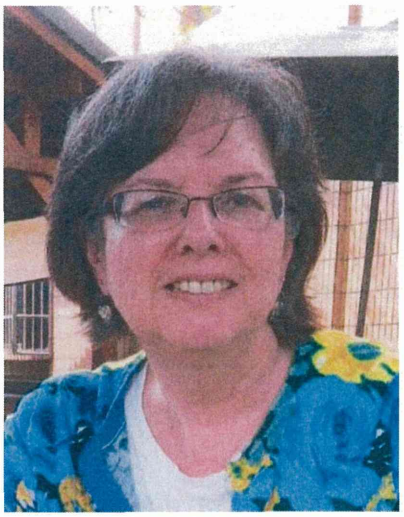
Michael Millington, Ph.D., CRC

Dr. Millington has 29 years experience in rehabilitation synthesizing practice, management, research, teaching and policy interests in U.S., Australia, and International venues. As a practitioner he is a recognized expert in vocational evaluation and rehabilitation counseling. He cofounded the Louisiana Business Leadership Network, a non-profit organisation that develops innovative employment and career strategies within the business community. He has been the author and lead investigator on a variety of capacity building grant projects in the United States including the redesign of the National Clearinghouse of Rehabilitation – Counseling Training Materials.

Research interests focus on issues of community inclusion of people with disabilities in any application including family interface with rehabilitation counseling; disability issues in the workforce (i.e. aging & mental health); developing intentional communities of practice in the service of knowledge translation, program management, and policy development; community engagement in psychiatric rehabilitation; advancing best pedagogical practice in inclusive distance education technologies, and advancing social network analysis as a tool in research and practice. Current research projects include: (a) Community-based approach to respite care for families; (b) community based-approach to supporting people with dementia; (c) mapping community mental health resources in Australia; (d) implementation of innovative monitoring and evaluation practices in community-based rehabilitation programs in middle and low income countries; and (e) action research approaches to the development of a global identity for rehabilitation counselors.

He received his Ph.D. in Rehabilitation Psychology from the University of Wisconsin Madison in 1993. Maintaining a role in academia since 1993, he has been an Associate Professor at Lousiana State University and Auburn University in thier respective rehabilitation counseling programs; and a Research Associate Professor at Utah State University. He is presently Senior Lecturer and Course Director in the Faculty of Health Sciences at Sydney University. He has over 50 peer reviewed journal publications, book chapters, and technical reports and manuals. He has authored two books, the most recent entitled, "Families in Rehabilitation Counseling: A Community-Based Rehabilitation Approach" (Millington & Marini, 2015). He is an Associate of the Centre of Disability Research and Policy in the Faculty of Health Sciences at the University of Sydney.

Terri A. Lewis, Ph.D.



Terri A. Lewis, PhD
PO Box 146 Silver Point TN 38582
Cell 931-267-3532
Cell TW 886 978 777 120
Skype terri.a.lewis
email tal7291@yahoo.com
Assistant Professor
National Changhua University of Education Changhua, Taiwan ROC

Dr. Lewis has extensive experience in the development and administration of community programs and systems of care for persons with disabilities and chronic health impairments. Her work life represents broad community rehabilitation industry experience, having served as a special education teacher; the Director of an overseas embassy based mental health program in the People's Republic of China; and collaborator with local, state, and federal agencies to create community mental health and rehabilitation services for unserved and underserved persons with a wide variety of needs. She actively consults with businesses around program improvement and has a particular interest and experience in: systems change; executive coaching; counselor education programs; evaluation and measurement; legal and regulatory issues; employee compensation and public benefits programs for persons with disabilities; international rehabilitation practices, and quality management and measurement.

At this time, she serves on the faculties of National Changhua University of Education in the Graduate Institute of Rehabilitation Counseling and Southern Illinois University Carbondale in the Rehabilitation Institute. She collaborates with vocational programs in the USA and southeast Asia on the design of community based rehabilitation with special emphasis on Allied Health care coordination. She holds a BS in Special Education from Heidelberg College in Tiffin, OH; an MS in Special Education, Multi-handicapped from Montana State University in Billings, MT; and a PhD in Rehabilitation from SIU Carbondale. Dr. Lewis serves as a consultant to the Office of International Programs and Cross Strait Affairs at NCUE. She is a member of the US Food and Drug Administration's Consumer Advisory and Selection Committee, and the SUMMIT, a rehabilitation program evaluation professional organization.

Ming Hung Wang, Ph.D., CRC

Ming Hung Wang, Ph.D., CRC is a professor and Director of Graduate Institute of Rehabilitation Counseling at the National Changhua University of Education, Taiwan. Dr. Wang is also serving as the director of the Vocational rehabilitation Resources Center, a research and supervision outreach center commissioned by the Workforce Development Agency, Ministry of Labor, Taiwan. He is the former president of Taiwan Vocational Rehabilitation Association (2011-2014).

Dr. Wang attained his Ph.D. at the University of WI-Madison in the Department of Rehabilitation Psychology in 1998. Some of Dr. Wang's primary areas of clinical interest and research include attitudes toward disability, value, supported employment, career counseling, case management, psychosocial aspect of disability, vocational assessment, and international rehabilitation.

Dr. Wang actively and enthusiastically participate international research cooperation programs and is currently serving as the editors for several international rehabilitation counseling journals. One of major tasks Dr. Wang doing is helping government to develop a better vocational rehabilitation service delivery system in Taiwan, such as certification, ethics, and continuation education for vocational rehabilitation professionals.

Jun Yaeda, Rh.D.

Dr. Jun YAEDA, is an associate professor of the Rehabilitation Course, Lifespan Developmental Sciences Program, Graduate School of Comprehensive Human Sciences, at the University of Tsukuba in Japan. He has worked in the field of rehabilitation for the past 30 years. He has over 100 professional publications in the fields of vocational rehabilitation, rehabilitation counseling, social work, and special needs education.

Currently he is the board member and the chair of the International Division of Japan Society of Vocational Rehabilitation and Japan Academy of Comprehensive Rehabilitation, the president of Japan Rehabilitation Counseling Association, and an international board member of GLADNET. He also serves on the advisory editorial boards of *Journal of Rehabilitation Research, Policy and Education (Springer Publishing Company), The Australian Journal of Rehabilitation Counselling (Cambridge University Press), and Japanese Journal of Vocational Rehabilitation (Japan Society of Vocational Rehabilitation).*

His areas of current interest include rehabilitation philosophy, rehabilitation collaboration, EBP training, vocational rehabilitation of the individuals with Early Onset Dementia (EOD) and Traumatic Brain Injury (TBI), curriculum development for rehabilitation counselors in Japan, and international rehabilitation counseling education and research.

He can be reached at: jyaeda@human.tsukuba.ac.jp

International Research Network Meeting

Work Support for Early Onset Dementia:

Policy, Practice, & Research In Australia

Michael Millington, Ph.D., CRC
Centre for Disability Research & Policy
Faculty of Health Sciences
University of Sydney
NSW, Australia

Executive Summary

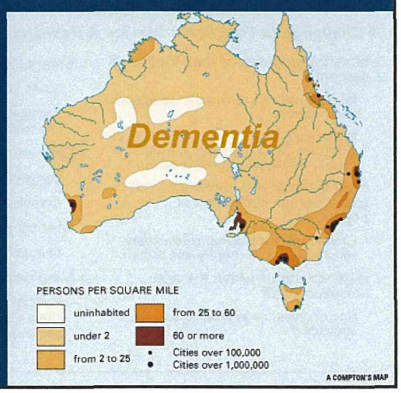
In Regards to Early (Younger) On-set Dimentia:

- 1. The development of specific vocational rehabilitation policy, practice and research is very limited.
- 2. What has emerged is a framework that allows vocational rehabilitation to evolve in a very community, family, and client centred way.
- 3. Practice innovation in supporting workers with early onset dementia seems to be best expressed in a single project "Side-by-Side"
  - Work supports become more activity based as symptoms and age increase.
- 4. Work supports can be thought of more broadly in a systems approach.
  - Most effective work-related support comes through the support of family carers
    - Respite, information, support, counselling, advice and helps consumers effectively engage with services appropriate to their individual needs.
  - The employment of carers is an important aspect that should be considered.

Key Facts & Statistics 2015

Dementia
- 342,800 current pop.
  - 25,100 Early Onset
- Growth reflects aging population:
  - 400k by 2025 (29,288)
  - 900k by 2050 (65,898)
- 1.2mil caring for PWD
  - 150k shortage by 2029
- Skyrocketing cost
  - >>1% GDP(2035)
  - 4.9 bil (2010)
  - 83 bil (2060)

- Research response
  - + 200 mil/5yr
  - 60 mill/yr total



National Framework for Action on Dementia

Priorities for Action (2006-2010)

- **Priority Area 1: Care and Support** services that are flexible and can respond to the changing needs of people with dementia, their carers and families.
- **Priority Area 2: Access and Equity** to dementia information, support and care for all people with dementia, their carers and families regardless of their location or cultural background.
- **Priority Area 3: Information and Education** that is evidence-based, accurate and provided in a timely and meaningful way.
- **Priority Area 4: Research** into prevention, risk reduction and delaying the onset of dementia as well as into the needs of people with dementia, their carers and families.
- **Priority Area 5: Workforce and Training** strategies that deliver skilled, high quality dementia care.

Framework for a Holistic Model

Community
awareness and acceptance
realise potential in all aspects of life
participate

Informal (Proximal) Care

Carers and family
capacity to cope
information and support
access to respite
education

Person with dementia

Formal (Distal) Care

Care and services
Easy, seamless access to:
information and support
early, appropriate diagnosis
and intervention
appropriate quality care

What's Working & Key Challenges

Tracking progress from 2011

What's working...
- Committed Workforce
- Current Support Programs
- Training & Education
- Consumer-directed care

Key Challenges
- Stigma and social attitudes
- Consumer engagement
- Consumer choice
- Increased competition
- Unmet needs
- Specialised support
- Reach and variability of support services
- Access
- Education and training
- Accreditation and quality of life indicators
- Funding