



News for and about MICL Research Partners, Advisory Panel Members and Related Folks

Greetings! This newsletter supplements the regular research progress reports provided by partners in the **Research and Training Center on Measurement and Interdependence in Community Living**. We publish the Update quarterly, so please send your news and notes whenever convenient. For the complete cast of characters, see the last page.

Presentations

Amanda Reichard has had a paper accepted for presentation at the Centers for Disease Control and Prevention's Division of Diabetes Translation Conference in April. Her subject is "Diabetes among Adults with Cognitive Limitations Compared to Individuals with No Disabilities in the U.S."

Members of the MICL team made the following presentations at the 137th American Public Health Association Annual Meeting and Exposition in Philadelphia, November 2009.

- Charles Drum presented "Development and pilot testing of the Outpatient Health Care Usability Profile (OHCUP)," which was coauthored with Willi Horner-Johnson and Amy Cline.
- Craig Ravesloot gave a presentation on "Measuring CIL Services that Improve Community Participation of People with Disabilities," a paper coauthored with Glen White and Chiaki Gonda.
- Glen White and Chiaki Gonda gave a poster presentation on "A scoping review of physical activity health promotion interventions for people with mobility impairments: Do interventions reduce secondary conditions and increase community participation?"
- Chiaki Gonda presented a poster titled "Reducing disparities in emergency preparedness and response for people with disabilities." This student poster presentation was organized by the Spirit of 1848 Caucus of the APHA.
- Dot Nary, KU doctoral student, and Chiaki Gonda presented the poster "Public health and people with disabilities: Where we are and where we need to go."

- Glen White, Chiaki Gonda, Jana Peterson, and Charles Drum presented the poster “What are the effects of these interventions on subsequent consumer participation in the community?”
- Amanda Reichard gave an oral presentation on “Disease prevalence and health care utilization patterns of people with physical disabilities in Kansas who receive support from an HCBS waiver.” She also made two poster presentations: “Preventive Screening and Preventive Health Care Utilization Patterns of Individuals with Disabilities Supported by Home and Community-Based Services in Kansas” and “A Model Assessment for Surveillance of Disease Prevalence and Monitoring Cost Utility and Health Outcomes of Individuals with Physical Disabilities Served by HCBS Waivers.”

In December 2009, Amanda Reichard gave the oral and poster presentations noted above at a statewide conference titled “Cultivating Healthy Kansans: A Leadership Summit on Health Promotion and Chronic Disease Prevention.”

At the Association of Programs for Rural Independent Living (APRIL) annual conference in San Juan, Puerto Rico, in October 2009, Glen White gave a presentation on his trip to Peru in January 2009. He also presented on the topic of “Cultural Diversity and Cultural Competence” at the APRIL Youth Pre-conference.

Publications

Charles Drum, Glen White, Willi Horner-Johnson and Genia Taitano published [“The Oregon Death with Dignity Act: Results of a literature review and naturalistic inquiry”](#) in *Disability and Health Journal* (Jan. 2010, Vol. 3, Issue 1, pp. 3-15).

A manuscript by Glen White and Chiaki Gonda titled “Moving from Independent to Interdependence: A Conceptual Model for Better Understanding Community Participation of Centers for Independent Living Consumers” has been accepted by the *Journal of Disability Policy Studies* and is in press.

Glen White and Chiaki Gonda submitted a manuscript entitled “A scoping review of physical activity health promotion interventions for people with mobility impairments: Do interventions reduce secondary conditions and increase community participation?” to the *Journal of Disability and Health*. This paper is written in collaboration with Charles Drum and Jana Peterson from OHSU. The authors have received a “revise and resubmit” notice from the journal editor.

Amanda Reichard and Hayley Stolzle submitted the following manuscript to the journal *Intellectual and Developmental Disabilities*: “A Comparison of Diabetes among Individuals with Cognitive Limitations and the General Population in the United States.”

Amanda Reichard and Hayley Stolzle submitted another manuscript to *Disability and Health Journal*: “Health Disparities among Adults with Physical Disabilities or Cognitive Limitations Compared to Individuals with No Disabilities in the United States.”

Collaboration

Alexa Stuijbergen, PhD, RN, FAAN, visited the KU RTC/IL in December 2009 through a Big 12 Faculty Fellowship. She is Dean and Interim at the University of Texas-Austin School of Nursing. Stuijbergen and the KU team discussed

their research interests and possible collaboration in the areas of health promotion and participation for people with disabilities.

Stuifbergen has been involved in research related to health promotion for persons with disabilities for more than 15 years. Her center grants and research projects studying health promotion in adults with chronic disabling conditions (multiple sclerosis, post-polio syndrome, and fibromyalgia) have been funded for over \$6.7 million by the National Institute of Nursing Research, the Center for Medical Rehabilitation Research, the National Institute of Child Health and Human Development, and the Office of Research on Women's Health at the National Institutes of Health.

Stuifbergen chaired the Adult Work Group for the DHHS Advisory Subcommittee to generate health promotion objectives for persons with disabilities for inclusion in Healthy People 2010.

Honors

Chiaki Gonda received an APHA student travel scholarship of \$1,000 to attend the American Public Health Association Annual Conference in November 2009. The competitive award was sponsored by the Association of University Centers on Disability and the Disability Section of APHA.

Service

Chiaki Gonda became a member of the youth steering committee for APRIL. She attends a monthly teleconference to discuss upcoming activities and plan for a youth-preconference to be held with the 2010 annual conference.

She is also involved in the organization's Youth Participation Project, which focuses on facilitating youth mentoring and youth representation at CILs. For this project, Gonda takes a lead on facilitating discussion, provides assistance and oversees project progress. This project is sponsored by the MICL grant and the final product will be presented at the State of the Science Conference in next fall.

In the Works

MICL partners and advisory members are now planning the RTC MICL's State of the Science conference.

“Community Participation by People with Disabilities: How Do We Measure Up?”

Oct. 28-29, 2010

Overland Park, Kansas (*outside Kansas City, Missouri*)

We'll be sending out information soon, so please forward it to everyone you think will be interested in attending. The conference will be held prior to APRIL's annual conference on Oct. 30-Nov. 1, so participants can attend two conferences with one trip.

New Ventures

The Kansas team has said farewell (but not good-bye) to Mike Fox, who was our associate director of health policy and is now on the staff at the CDC in Atlanta. He is Director for Science in the Division of Human Development and Disability within the Center on Birth Defects and Developmental Disabilities.

He continues to collaborate with Amanda Reichard, Glen White and Martha Hodgesmith on selected projects, and is still a tenured full professor in KU's Health Policy and Management program, where he is taking phased retirement.

The Kansas Living Well with a Disability program is collaborating with the National Center on Physical and Disability (NCPAD) to provide a new training for Living Well facilitators. Staff from the Chicago-based NCPAD will provide webinars later this spring to train facilitators to lead a 14-week exercise program that is tailored to the needs of their consumers.

This exercise program will enable our facilitators to continue building on the success and motivation that consumers experience in the Living Well course.

The KU Living Well program has also created a Facebook page for Kansas Living Well with a Disability facilitators. We encourage all research partners and colleagues to become a "friend" and add resources to [Living Well in Kansas](#).

Who's who in the Research and Training Center on Measurement and Interdependence in Community Living (RTC/MICL).

University of Kansas Research and Training Center on Independent Living:

Glen W. White, PhD, director, co-investigator
Amanda Reichard, PhD, research director
Martha Hodgesmith, JD, associate director
Dick Saunders, PhD, senior scientist
Muriel Saunders, PhD, assistant research professor
Val Renault, MA, information/dissemination coordinator
Catherine "Cat" Howland, MS, project coordinator
Pam Willits, grants specialist
Leslie Schmille, BS, project assistant
Chiaki Gonda, graduate research assistant
Hayley Stolzle, graduate research assistant

University of Montana Rural Institute on Disabilities:

Tom Seekins, PhD, co-investigator
Craig Raveslout, PhD, research associate

Oregon Health and Science University:

Charles Drum, J.D., PhD, co-investigator
Willi Horner-Johnson, PhD, assistant professor
Danielle Bailey, MPH, research assistant
Denise Spielman, BA, AAS, Senior Research Assistant
Amy Cline, MPH, dissemination coordinator

Washington University in St. Louis, School of Medicine:

David Gray, PhD, co-investigator
Holly Hollingsworth, PhD, statistician
Jessica Dashner, OTD, OTR/L, research associate
Denise Curl, BA, data manager

U.S. Department of Education:

David Keer, Program Specialist
Co-chair, Interagency Subcommittee on Disability Statistics, Office of Special Education and Rehabilitative Services

MICL Advisory Panel:

Fabricio E. Balcazar, PhD
Gwen Gillenwater
Linda Gonzales, MA
Robert Michaels
Jean Ann Summers, PhD
Betsy Valnes

We want your news! Send it to Val Renault, vrenault@ku.edu, 785-864-0575.