



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 aim to publish the Update quarterly, so please send your news and notes whenever convenient. For the complete cast of characters, see the last page.

Presentations

Charles Drum gave the keynote speech on Oct. 1 at the 2009 Southwest Conference on Disability in Albuquerque. The conference theme was “Disability in America: Inalienable Rights for All.”

Drum made two invited presentations at the 2009 CDC Disability and Health Seminar in Atlanta: “The Oregon Community Engagement Initiative” and “Development and Validation of the Outpatient Health Care Usability Profile.”

Glen White spoke about independent living at the Conference on the United Nations Convention on the Rights of Persons with Disabilities on July 22 in Washington, D.C. His talk was part of a panel that examined the opportunities for U.S. disability advocates and other interested individuals to assist in promoting livable communities in other countries in the context of CRPD implementation.

On September 16, White was one of the facilitators on a teleconference titled “United Nations Convention on the Rights of Persons with Disabilities: What it Means to IL.” This was part of a series of IL conversations hosted by APRIL in cooperation with ILRU and NCIL.

The National Youth Leadership Network (NYLN) hosted a teleconference titled “Independent Media 2.0” on Sept. 21. Speakers in the national call discussed using blogs, video and free social media tools (podcasting, Twitter, Facebook) to revolutionize and remix a powerful disability rights message.

Advisory Panel member **Betsy Valnes** is Executive Director of NYLN (<http://www.nyln.org>).

Mike Fox helped facilitate a national meeting of the National Paralysis Taskforce in Washington, D.C. on July 21-23, which was attended by about 80 stakeholders from around the country. The Christopher and Dana Reeve Foundation presented results of a recent national survey that used a new, functional definition of paralysis to find a paralysis prevalence rate of approximately 4.9 million in the U.S.

He also presented information on emergency preparedness projects conducted by the Research and Training Center on Independent Living at the National ADA Symposium held in Kansas City on June 9.

Publications

MICL research partner **Charles Drum** and Advisory Panel member **Fabricio Balcazar** have both edited new textbooks:

Drum, C.E., Krahn, G.L., & Bersani, H. Jr. (Eds.). (2009). *Disability and Public Health*. Washington, D.C.: American Public Health Association Press.

Balcazar, F.E., Suarez-Balcazar, Y., Talyor-Ritzler, T., & Keys, C.B. (Eds.). (2010). *Race, Culture and Disability: Rehabilitation Science and Practice*. Boston: Jones and Bartlett Publishers.

Drum's book is the first public health textbook that focuses on disability. It was reviewed in the August issue of *The Nation's Health*, the APHA newsletter, and will be endorsed on the Robert Wood Johnson web site. In addition to editing the text, Drum authored or coauthored three chapters: "An Introduction to Disability and Public Health," "Models and Approaches to Disability," and "Health of People with Disabilities: Determinants and Disparities" (with Willi Horner-Johnson, also of OHSU).

Glen White contributed a chapter to the book titled "Nobody Left Behind: Disaster Preparedness and Public Health Response for People with Disabilities."

White and **Tom Seekins** also contributed to Balcazar's book. White coauthored a chapter titled "Exploring Cultural Competence: Implications for Research" and Seekins coauthored "Community Infrastructure and Employment Opportunities for Native Americans and Alaska Natives."

Charles Drum also published this article:

Drum, C.E., Krahn, G., Horner-Johnson, W., Ritacco, B., Berardinelli, M., Wasfi, R., & Pickett-Cooper, P. (2009). The Oregon community engagement initiative: A multi-case study of a disability coalition development process. *Community Development*, 40: 3-19.

Amanda Reichard coauthored an article that has been accepted for publication in *Disability and Health Journal*. "Quality of diabetes care for adults with developmental disabilities" was authored with Theresa I. Shireman, Allen Greiner, Jim Backes, and Niaman Nazir, all at the University of Kansas Medical Center.

Glen White and **Val Renault** wrote an article about White's trip to Peru in January '09 with an American "IL Dream Team" that appears in the November issue of *New Mobility*. Check <http://www.newmobility.com/index.cfm> for the current issue (not yet posted as of this writing). The article is titled "Independent Living: From Kansas to Peru."

MICL research partners have authored and co-authored several new fact sheets produced by the Research and Training Center on Disability in Rural Communities at the University of Montana Rural Institute.

Nursing Home Emancipation: A Preliminary Study of Efforts by Centers for Independent Living in Urban and Rural Areas discusses a national survey that was conducted to identify and assess current CIL nursing home transition policies, procedures, and practices. Authors include **Tom Seekins**, **Craig Raveslout**, and **Glen White**. Advisory panel members Linda Gonzales and Gwen Gillenwater contributed to the project (<http://rtc.ruralinstitute.umt.edu/IL/Nursing%20Home%20Preliminary%20Technical%20Report.htm>).

Tom Seekins was an author on *Developing Methods and Measures to Assess Progress in Achieving Access Goals of the Americans with Disabilities Act: A Case Study of Small Towns in Montana* (<http://rtc.ruralinstitute.umt.edu/IL/ADACaseStudy.html>).

Working Well with a Disability is a progress report on an adaptation of the successful Living Well with a Disability health promotion curriculum, which was developed by **Craig Raveslout**, **Tom Seekins**, and **Glen White**. For the 10-week Working Well workshop, counselors in 20 VR offices in five states recruited clients to participate in a randomized controlled trial (<http://rtc.ruralinstitute.umt.edu/SelEm/factsheets/WWwithadisability.html>).

Grants

Researchers at the KU RTC/IL have been awarded two U.S. Department of Education NIDRR grants worth more than \$1 million. The field-initiated projects focus on self-advocacy and weight loss.

Glen W. White, PI, **Jean Ann Summers**, MICL Advisory Panel member, and **Cat Howland** received \$598,770 for three years to develop a training technology based on the Americans with Disabilities Act. The training will provide students with disabilities at KU and Kansas State University the knowledge and skills to acquire the ADA accommodations they need to succeed in postsecondary educational settings. KU's eLearning Design Lab will partner on this project, under the direction of Ed Meyen.

Muriel Saunders, PI, **Amanda Reichard**, and **Richard Saunders** received \$599,467 for three years to implement and study a weight loss program for people with physical disabilities in Wichita. The project will educate participants about a diet for weight loss and weight management, and then evaluate the health outcomes of resulting weight loss. Researchers at the KU Medical Center are also co-investigators on the project.

Mike Fox helped Together Prepared of Douglas County, Kansas, write an emergency management proposal that was funded by the National Libraries of Medicine. The two-year grant for the Together Prepared working group allows the Douglas County Health Department to partner with the Lawrence Public Library to expand outreach and communications during emergencies for vulnerable populations in the county.

Honors & Awards

Charles Drum received the National Distinguished Disability Research Award from the Southwest Conference on Disability, where he was also the keynote speaker. This award recognizes an individual from the United States who has compiled a distinguished record of disability-related

research in the social or physical sciences that has contributed to and advanced our overall knowledge of disability. The award was presented at the 2009 conference in Albuquerque on September 30.

Fabricio Balcazar received a Commendation Award from the National Association of Rehabilitation Research and Training Centers at the annual meeting in May 2009. The honor recognized his important contributions and achievement in research, teaching, service and advocacy on behalf of persons with disabilities.

In the News

Glen White was profiled in the *Lawrence (KS) Journal-World* on Aug. 18, 2009. The article “KU professor advocates accessibility around the globe” detailed his involvement with the Peruvian disability movement (<http://www2.ljworld.com/news/2009/aug/18/ku-professor-advocates-accessibility-around-globe/>).

Service

Charles Drum currently serves on these councils and committees:

- Healthy People 2020 Disability and Health Workgroup National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia
- Non-Federal Disability Comparative Effectiveness Research Group, Federal Coordinating Council on Comparative Effectiveness Research, US Department of Health and Human Services, Washington, DC
- Advisory Committee, Research and Training Center on Disability in Rural Communities, University of Montana
- Governing Council, American Public Health Association
- Constituent Committee, Office on Disability, US Department of Health and Human Services, Washington, DC

Gatherings

MICL’s principal investigators and other project staff met Oct. 21-23 in St. Louis to discuss research progress and directions. Thanks to David Gray and Jessica Dashner at Washington University in St. Louis for hosting the two days of meetings.



Front row, left to right: Martha Hodgesmith, Glen White, Jessica Dashner, David Gray. Back row: Craig Raveslout, Charles Drum, Amanda Reichard, Chiaki Gonda, Tom Seekins, and Don Lawlor from the CDC.

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

At the 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
Mike Fox, ScD, 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

At the University of Montana Rural Institute on Disabilities:

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

At the 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

At the 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

At the U.S. Department of Education:

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

And serving on the 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.

* * *

*When one tugs at a single thing in nature,
he finds it attached to the rest of the world.*

- John Muir