



AUCD

Health & Disability Digest

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In the News

CDC Funds New Grants for Fragile X Clinical and Research Consortium

The New York State Office for People With Developmental Disabilities' (OPWDD) Institute for Basic Research in Developmental Disabilities (IBR) has been selected to receive a \$2.2 million, four-year cooperative agreement grant from the National Center on Birth Defects and Developmental Disabilities (NCBDDD) of the Centers for Disease Control and Prevention (CDC) for research on fragile X syndrome. The project will build on a collaborative, research-oriented infrastructure that has been established with funding from a previous CDC contract that is now in its final year. In the new project, collection of pilot longitudinal data will be based on direct interaction with, and medical evaluation of, patients who receive services at clinics in the Fragile X Clinical and Research Consortium (FXCRC). [View Press Release.](#)

Highlights from the Network: **Research and Training Center on Disability in Rural Communities at the University of Montana Offers New Training on Working Well with a Disability**



The Working Well health promotion program is designed for adults with disabilities who want to be employed. The program is delivered over 6 to 7 weeks, using a similar workshop format to Living Well. The workshop helps people with disabilities manage or reduce secondary conditions that affect their employment and other life activities. Working Well builds on concepts introduced in the Living Well workshop, but tailors the information to individuals preparing for, or trying to

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maintain, employment. Working Well was built on the premise that life balance and health maintenance are important to address when taking on new employment-related activities.

Working Well research found that participants most affected by secondary conditions, who actively participated in the Working Well program, experienced significant reductions in limitation from secondary conditions. These reductions may enhance their employment outcomes. From the literature, we know that higher rates of secondary conditions are associated with worse employment outcomes (Ipsen, et al., in press; Kaye, 2009). The RTC: Rural will be offering online training opportunities in December 2011 and January 2012 to individuals from various service agencies to become certified Working Well workshop facilitators. To receive more information, program updates, and to join the Working Well with a Disability list serve, please contact: Tracy Boehm at boehm@ruralinstitute.umt.edu or (406) 243-5741.

Fellowship Reflections From Ismaila Ramon, AUCD-NCBDDD Disability Surveillance and Epidemiologic Research Fellow

By Ismaila Ramon

The [AUCD-NCBDDD Surveillance and Epidemiology Fellowship](#) offers fellows the opportunity to work at NCBDDD under the supervision of top experts in the field. My experience with the fellowship stands out as a life-changing one. The supportive environment at NCBDDD fosters mentoring and the training in public health and disability is filled with profound depth and breadth. The fellowship experience enhanced my competencies and taught me critical leadership skills. I have been actively involved in projects that extend surveillance activities and increase understanding of the unmet needs of people with disabilities. I was able to harness health assessment skills; skills that are applicable in almost any public health initiative requiring formative evaluation. A prime example of this stems from my role in an international effort to improve health surveillance data on people with intellectual disabilities in the United States. I engaged in assessment activities that highlighted the needs and challenges of studying people with intellectual disabilities. I was involved in the dissemination of vital information through manuscript development and conference presentation. Through my work in data analysis, I was exposed to national surveillance systems. My deep involvement with the DHDD's Disability Policy, Intervention and Programs team presented unique opportunities to learn about policy development. [Read more.](#)



AUCD Change of Address

Effective Monday October 3, 2011 AUCD will have a new address across the street from its current location in Silver Spring,

[State Disability & Health Grantees](#)

[NCBDDD RTOIs](#)

[Intellectual Disability Surveillance Efforts](#)

Feature Resource

Have you visited AUCD's [Health Reform Hub](#) recently?

The Hub is an online gateway developed by AUCD to provide technical assistance and information about the Patient Protection and Affordable Care Act (PPACA). Be sure to check the "Related Links" section at the bottom of the Health Reform Hub!

Maryland:

Association of University
Centers on Disabilities
1100 Wayne Avenue, Suite
1000
Silver Spring, Maryland 20910



Please note that telephone and fax numbers as well as email addresses will remain the same. Should you have any questions do not hesitate to contact [Danielle Webber](#).

Events from the Network:
AUCD's Health and Disability Special Interest Group (SIG) Webinar:
Transitioning Youth and Young Adults from Pediatric to Adult Health Care Systems

Date: Monday, October 17, 2011

Time: 12:00 – 1:00pm Eastern

[Register today!](#)

This webinar will discuss existing approaches to transitioning youth and young adults from pediatric to adult health care systems. The webinar is supported by the Health and Disability SIG, but all are welcome to register and attend. Presenters:

- Mary R. Ciccarelli, M.D., Director of the Center for Youth and Adults with Conditions of Childhood at the Indiana University School of Medicine, Associate Chair of Pediatric Education and Associate Professor of Clinical Medicine-Pediatrics
- Cory E. Nourie, M.S.S., M.L.S.P., Patient Transition Social Work Coordinator for the Division of Transition of Care at Nemours/Alfred I. duPont Hospital for Children in Wilmington, Delaware
- Stacey Milbern, Community Outreach Director, National Youth Leadership Network
- Carl Cooley, M.D., Co-director, Got Transition – the National Health Care Transition Center

And don't forget...

Check out the Health and Disability Special Interest Group (SIG) at [AUCD's Annual Meeting](#). All are invited to join the discussion, on **Tuesday, November 8th from 12:00 pm to 1:15 pm EST.**

Inclusive Nutrition and Physical Activity Programs Webinar

Date: Tuesday, October 18, 2011

Time: 1:00pm - 2:00pm Eastern

[Register today!](#)

Healthy eating and physical activity are important aspects of all peoples' lives, including people with disabilities. This webinar will feature the National Center on Physical Activity and Disability (NCPAD), a resource center dedicated to providing physical activity and nutrition programs that acknowledge and address the individual needs of every person. NCPAD will share their program successes and offer ideas for inclusive programs at the community and local level. Join the webinar for an engaging discussion on including people with disabilities in your health promotion efforts.

This webinar is part of a Resource Center Highlight Series sponsored by the State Disability and Health Grantees and is co-hosted by the Obesity and Physical Activity for People with Disabilities Learning Community at the National Association of County and City Health Officials (NACCHO).

Health & Disability Digest Submissions

Would you like to share important updates or innovative practices from your program?

Health & Disability Digest invites you to submit notable information from your project including information about your staff, network wide requests, upcoming or past events, available positions, new research developments, and resources. Articles can be submitted using the [online form](#) or emailed to [Danielle Webber](#).

