



AUCD

# Health & Disability Digest

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## *In the News*

### HHS Announces New Draft Standards to Improve Monitoring of Health Data

HHS Secretary Kathleen Sebelius has announced new draft standards for collecting and reporting data on race, ethnicity, sex, primary language and disability status, and announced the administration's plans to begin collecting health data on lesbian, gay, bisexual and transgender (LGBT) populations. Both efforts aim to help researchers, policy makers, health providers and advocates to identify and address health disparities afflicting these communities. "Health disparities have persistent and costly effects for minority communities, and the whole country," Secretary Sebelius said. "Today we are taking critical steps toward ensuring the collection of useful national data on minority groups, including for the first time, LGBT populations. The data we will eventually collect in these efforts will serve as powerful tools and help us in our fight to end health disparities." Under the plan, HHS will integrate questions on sexual orientation into national data collection efforts by 2013 and begin a process to collect information on gender identity.

The public may submit comments for the draft minority data collection standards at [www.regulations.gov](http://www.regulations.gov) under docket number HHS-OMH-2011-0013. Public comments will be accepted until August 1. Information is also available at [www.minorityhealth.hhs.gov/section4302](http://www.minorityhealth.hhs.gov/section4302).

### *Highlights from the Network:* UCLA Project Step Up for Teens with Fetal Alcohol Spectrum Disorders

Mary J. O'Connor, PhD, ABPP, UCLA researcher and expert in the field of Fetal Alcohol Spectrum Disorders, is currently heading a 3-year investigation testing the efficacy of Project Step Up, a brief intervention designed to reduce/prevent alcohol consumption and alcohol-related negative outcomes in adolescents with prenatal alcohol exposure. The study is funded by the National Center on Birth Defects and Developmental Disabilities of the Centers for Disease Control and Prevention. Project Step Up at UCLA was developed to address the high risk for alcohol misuse in adolescents with prenatal alcohol exposure. This brief (6-week) group intervention provides adolescents with knowledge about alcohol-related consequences, fosters skills to cope

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## Quick Links

[State Disability & Health Grantees](#)

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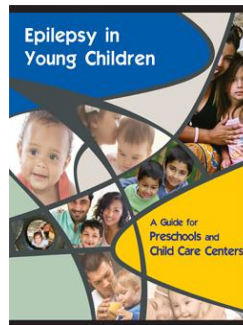
[Act Early Ambassador Project](#)

[AUCD Employment Opportunities](#)

effectively with stress, and promotes adaptive responses to alcohol-related social pressures. Caregiver group topics include the effects of prenatal alcohol exposure on the developing brain, how to develop a positive parent-teen relationship, supportive community resources, and how to handle parenting challenges unique to adolescents with prenatal alcohol exposure. The program is anticipated to provide an effective, acceptable, cost-effective model for the prevention of negative alcohol-related outcomes in adolescents with prenatal alcohol exposure. Interested providers and families are welcome to call (310) 825-8738 for further information or visit the [Step Up Website](#).

## Project Access: USC UCEDD at Children's Hospital Los Angeles

Over the past six years the USC UCEDD at Children's Hospital Los Angeles has worked to improve access to care for children/youth with epilepsy in California as well as Alaska, Nevada and Wyoming through federally-funded Project Access. The goal of the project is to improve access to health care services for children/youth with epilepsy as well as to eradicate often-associated stigma through increasing public awareness and understanding of the



disorder and improving the quality of services. Project Access, in partnership with the Epilepsy Foundation of Northern California, has developed a variety of tools in multiple languages. Materials have been created specifically for teachers and caregivers of young children. "Storybooks About Epilepsy" is a descriptive list of engaging children's books suggested to help children and their classroom peers to understand epilepsy. Also available, "Epilepsy in Young Children: A Guide for Preschools and Child Care Centers" is a booklet for teachers, daycare centers, and caregivers that provides information on taking care of young children with epilepsy. Both of these resources can be [accessed and printed for free](#). For more information please contact Cary Kreutzer, MPH, RD at [ckreutzer@chla.usc.edu](mailto:ckreutzer@chla.usc.edu).

## National Women's Health Week 2011 at OH UCEDD

This May, for the third year in row, the University of Cincinnati (UC) University Center for Excellence in Developmental Disabilities (UCEDD) in the Division of Developmental and Behavioral Pediatrics at Cincinnati Children's Hospital joined the U.S. Department of Health and Human Services Office on Women's Health in celebrating National Women's Health Week 2011. National Women's Health Week encourages women to take charge of their own health and learn ways to improve their physical and mental health and lower their risks of certain health problems. This year the UC UCEDD offered two Women's Health Week programs specially designed for women in the Greater Cincinnati area with developmental disabilities. The programs offered training in safety, healthy eating and fitness. Local experts from the Cincinnati Police Department, Nutrition Council of Greater Cincinnati and Cincinnati Recreation Commission Therapeutic Recreation were guest speakers. This year, by

popular demand, two programs were offered. On May 6 the third annual Spring into Action 3, was held and attended by 45 women ages 16-29 with developmental disabilities. On May 13, 48 women ages 30-44+ gathered for Be Safe. Be Smart. Be Strong. In 2009 and 2010, the UC UCEDD Women's Health Week day-long programs attracted over 175 women with developmental disabilities. For more information about the programs, contact Tena Benson, RN, MPH [tena.benson@cchmc.org](mailto:tena.benson@cchmc.org).

### 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 Edson](#).

