

## Alaska's Volcano and Floods

Alaska's Mount Redoubt volcano erupted a few months ago blowing ash as high as 9.5 miles into the sky, but the state's most recent challenge has been an unusually warm spring thaw that triggered floods.




Rebecca Hilgendorf

Senior and Disabilities Services sent out an update thanking everyone who contacted them with offers to help displaced individuals and/or those who lost their homes and belongings in the recent floods in Alaska's interior.

"A disaster declaration for the flooded

areas has been made and Homeland Security has assigned two people from the State Emergency Coordination Center (SECC) to coordinate relief efforts at Tanana Chiefs Conference (TCC) in Fairbanks," the update said. "To ensure that efforts are coordinated, that what is being shipped meets the current needs of the villages, and to avoid duplications all requests for food or supplies are routed through our local contacts from the SECC. The Villages have their appointed Point of Contact persons who are routing the village requests to the SECC, as well."

Senior and Disabilities Services Director Rebecca Hilgendorf reports that flood waters are going down, the volcano is quiet, and they've had sunshine for almost two weeks straight now. 

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# Maryland Rosewood Center Closed

On Friday, May 22, the very last resident of Maryland's Rosewood Center moved out. That's well ahead of the Center's scheduled June 30 closure date.

"I am very pleased," said Maryland Developmental Disabilities Administration (DDA) Director Michael Chapman. "Six weeks ahead of schedule!"

Governor Martin O'Malley signed an Executive Order January 15, 2008 to close the state-run Rosewood Center that had been serving individuals with developmental disabilities in Maryland for more than 100 years (see **CSR** February 2008). The FY 2009 budget approved by the state's General Assembly eliminates the budget for the



Martin O'Malley

Center with the beginning of the new fiscal year (July 1, 2009).

Now, three state residential centers remain in Maryland — the Holly, Potomac, and Brandenburg Centers with approximately 170 residents with developmental disabilities. Maryland serves an additional 22,000 individuals with developmental disabilities in community placements. Many of the individuals who live in the community have the same level of disability as those who resided at Rosewood or the other centers, a DDA report said.

Visit [DDA's website](#) to read the [Rosewood Closure Plan](#) and other [Rosewood information](#).

## NASDDDS Co-sponsors Dual Diagnosis Conference

NASDDDS will be one of the co-sponsors for the [National Association for the Dually Diagnosed's 26th Annual Conference & Exhibit Show](#) that takes place October 21-23, 2009 at the Royal Sonesta Hotel in New Orleans, Louisiana. The conference theme is "Advancing Mental Wellness through Excellence in Mental Health Care in Persons with Intellectual Disabilities."

## NASDDDS

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## Peter Bisbecos Elected Member of NASDDDS Board of Directors



Peter Bisbecos

The National Association of State Directors of Developmental Disabilities Services' Board of Directors elected Peter Bisbecos May 12 as member at large to the Board. When confirmed by NASDDDS membership at the Association's fall annual conference, the tenure of Mr. Bisbecos' service to the Board in this capacity will be extended to November 2010.

Peter Bisbecos is the Director of the Division of Disability and Rehabilitative Services (DDRS) in the Indiana Family and Social Services Administration and is responsible for the majority of disability services offered by the State of Indiana.


"I am delighted that Peter will be joining our Board of Directors as an at large representative," Board President Kenneth Ritchey said. "His experience, leadership, and perspective will make our organization that much stronger. This also gives the mid-western region a strong voice in helping develop public policy on various developmental disabilities issues."

Mr. Bisbecos has spent his career in and around

public service. After graduating from Indiana University School of Law at Indianapolis in 1987, he joined the Marion County Prosecutor's staff where he prosecuted at all levels, including a focus on felony narcotics, drunk driving, and introducing a federal drugged driving interdiction program to Indiana.

In 1992, Mr. Bisbecos joined the administration of Indianapolis Mayor Stephen Goldsmith. His initial focus was on improving public transit and Americans with Disabilities Act paratransit. He served in several other capacities in the Goldsmith administration, ultimately serving as a Special Assistant to the Mayor for public policy.

Bisbecos has been active in the community for most of his professional career. He has served on the Indianapolis Mayor's Help America Vote Act Local Advisory Council on Polling Place Accessibility and the following boards: the Indiana Leadership Forum, the Indianapolis Public Transportation Corporation, Easter Seals Crossroads Rehabilitation Center, and the Council of Volunteers for Hoosiers with Disabilities (COVOH).


"I am honored and gratified to serve in this capacity," Mr. Bisbecos said. "NASDDDS is a highly respected organization and has played a significant role in improving the lives of people with developmental disabilities." 

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## Alabama Celebrates New Department Name, Removes "R" Word

Alabama's legislature unanimously passed a bill April 14 to remove the "R" word from the Department of Mental Health's name.


"We are now simply the Department of Mental Health, and within the Department is our Division of Intellectual Disabilities," explained Associate Commissioner of the Division of Intellectual Disabilities Cathy Crabtree. "We are thrilled, to put it mildly!"

The Division of Intellectual Disability Services changed its name last year, but to change the department's name legislation had to be passed. 

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## New York Launches Free Affordable Housing Website

New York's Department of Health and Office of Mental Retardation and Developmental Disabilities has launched [nyhousingsearch.gov](http://nyhousingsearch.gov), a free website to search for and advertise affordable rentals and housing for people with special needs.

The initiative also includes toll-free numbers: (877) 428-8844 or (877) 428-8844 for Spanish speakers (staffed weekdays from 9:00 AM to 8:00 PM). 

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## Workers First

By Chas Moseley, NASDDDS Associate Executive Director

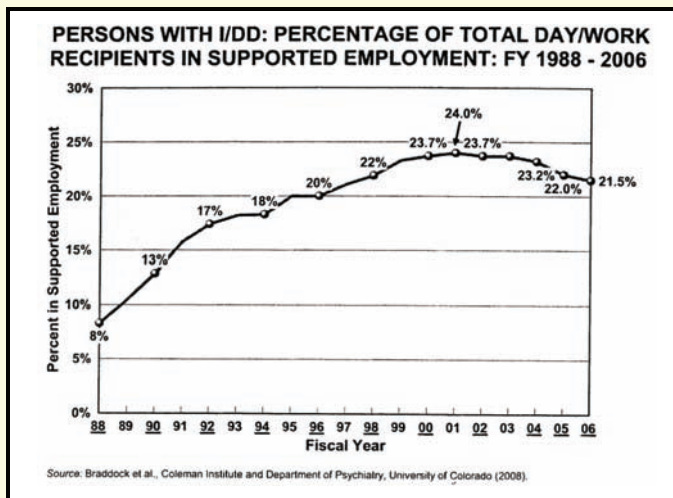


Chas Moseley

**What Does Work Mean?** Several years ago, I interviewed a number of workers with serious intellectual disabilities who held regular jobs in a variety of local businesses including a fast food restaurant, a library, a hotel kitchen, a bottle recycling plant, and others. All were being paid at least the minimum wage. What did work mean? The men and women that I interviewed described their jobs and their lives, hopes, and dreams in the same ways that most people do. Although each person's perspective differed, employment was important to them because of the purpose and organization that the work gave to their lives, the opportunities that it offered for friendships both on and off the job, and because it provided the means for them to buy things for themselves and their families.

What they talked about the most, however, was the feeling that the job gave them, a feeling of membership and companionship with their co-workers. Walt, who worked in the library, put it this way, "I like being with the books and being upstairs here...[but] the best part is working with the people I know." Workers identified with the tasks they performed, the companies that employed them and the friendships they had with their colleagues on the job. They described themselves as being "workers first," just like everyone else, and referred to their previous experiences in the workshop and day programs as being just a "trainee," a "participant," or a "client."

**Work Matters.** Employment has always been on the service agenda for state developmental disabilities agencies. But the focus on improving the numbers of individuals with ID/DD working in integrated jobs in the community as a priority policy goal has varied over time and across states. State DD agency policymakers have noted with concern that although the actual numbers of people with developmental disabilities in integrated community jobs increased slightly over the past several years, the percentage of individuals served in state DD systems who are employed in regular community jobs actually fell during the same period from its peak of 24% in 2001 to 21.5% in 2006. Equally disturbing are data suggesting that the focus of service provision has, in many regions, shifted away from employment and job supports to segregated day activity and workshop programs that do not assist participants in accessing a productive career path and meaningful work in the community.



**Employment First.** In an effort to reverse this trend, several forward thinking state developmental disabilities agencies are implementing comprehensive "Employment First" policies to focus funding and service delivery on improving employment outcomes among individuals with DD receiving support. Employment First strategies consist of a clear set of guiding principles and practices promulgated through state statutes, regulations, and operational procedures that target employment in typical work settings as the priority for state funding and the purpose of supports furnished to persons with developmental disabilities during the day. Employment First policies anchor the service delivery system, focusing funding, resource allocation, training, daily assistance, and even the provision of residential supports on the overall objective of employment, strengthening the capacity of all individuals receiving publicly financed supports to enter the workforce and become contributing members of society.

Washington State's Working Age Adult Policy identifies employment as the only day service that will be

(Workers First continued on page 5)

*Each individual will be supported to pursue his or her own unique path to work, a career, or his or her contribution to/participation in community life. All individuals, regardless of the challenge of their disability, will be afforded an opportunity to pursue competitive employment.*

Washington State - Working Age Adult Policy

(Workers First continued from page 4)


supported by the state developmental disabilities agency. Although the policy does not exclude funding for sheltered workshops and other services emphasizing community participation, support is contingent upon each person being on a “path to employment” and that services that be designed to enable them to reach their individual employment goals. Other states, following Washington’s lead, are crafting Employment First strategies to ensure that persons with the most intensive disabilities are not excluded from needed services during the day.

**Making it Happen.** State Employment First policies target a wide range of operational practices, funding methodologies and training procedures that are designed to increase the number of individuals with developmental disabilities who are employed in integrated community jobs. Policies adopted or under consideration by states include key provisions that:

- Identify integrated employment as the primary service option for adults receiving Day Habilitation Services and Supports (CO).
- Require integrated employment to be addressed in each recipient’s Individual Service Plan (CO).
- Set performance goals identifying specific increases in the percentage of individuals with developmental disabilities working in integrated employment within a designated time frame (FL, AZ).
- Establish standards identifying full-time employment as the optimal outcome of day service delivery (OK).
- Establish regulatory provisions ensuring that persons with intellectual disability have full access to employment and the training necessary to sustain employment (PA).
- Identify employment as the first day service that should be explored (TN).
- Include regulations ensuring choice and assistance to help people find and change jobs (TN).
- Require that services support a job for everyone who wants one (TN).
- Set gainful employment in integrated community settings as the primary service option for working-age adults and require steps to be taken toward integrated employment for those individuals not currently working in such settings (WA).
- Require special authorization to receive funding for non-employment service options (WA).
- Employment First policies represent a significant step in states’ efforts to improve integrated employment outcomes for persons with developmental disabilities receiving publicly financed support. Employment First represents a commitment by states, and state developmental disabilities agencies, to the propositions that all individuals with developmental disabilities: (a) are capable of performing meaningful work in typical integrated employment settings; (b) should receive as a matter of state policy employment related services and supports as a priority over other non-work related day services, and (c) should be paid at minimum or prevailing wage rates.

*Employment is the first day service option that should be explored for adults in the Division of Mental Retardation Services, Medicaid or state funded supports. Employment will always be considered as the appropriate outcome for an adult. Employment services and supports are viewed as the most appropriate service unless there is a compelling reason for recommending another service.*

Tennessee Division of Mental Retardation Services

Employment is important in everyone’s lives. For persons with intellectual and developmental disabilities, having a regular job in a local company, store, or business means membership in the community and is the critical element to people “having a life.” 

## Autism Updates

**ALABAMA**'s state senate passed the [Alabama Autism Support Act](#) on April 16 that would establish a permanent Council facilitating greater support for individuals with autism and Asperger syndrome. House Bill 150 aka House Joint Resolution 3 outlines the composition of a Council whose members the governor would select, including three adults with autism and three parents of children with autism.

The Council's work would involve developing a long-term plan, reviewed annually, for a comprehensive statewide system of care, which, to the extent practical, is derived from scientific-based research and nationally recognized best practices.

The plan would include:

The development and recommendation of a coordinated program of services;

- A comprehensive fiscal review, analysis, and recommendations for state spending on programs and services for ASD (autism spectrum disorder);
- The encouragement of interagency collaboration, public participation, and mutual sharing of information to facilitate policy decisions; and
- The implementation of a plan for a comprehensive statewide system of care to individuals with ASD.

**CONNECTICUT**'s Department of Developmental Services released a report on the progress of its Autism Pilot Project saying that an increased number of participants became employed and their attitudes about work improved. They received and used more services, particularly for employment and recreation, and increasingly participated in their communities. They significantly improved their social interactions and communication and living skills during their first year in the program. For some, "emotional problems diminished over the course of the year," the report said.

[An Evaluation of the Autism Pilot Program of the Division of Autism Services of the CT Department of Developmental Services](#), was conducted by the University of Connecticut Health Center.

**KANSAS**' legislative session ended before Kate's Law, [House Bill 2367](#) for insurance coverage of

autism services, could make it out of the House or Senate.

**MONTANA - 10th State to Pass Autism Insurance Bill!!** Montana Governor Brian Schweitzer signed an autism bill into law April 24 that requires private health insurance companies to provide coverage for the diagnosis and treatment of autism spectrum disorder.

[Senate Bill 234 aka "Brandon's Bill"](#) will require insurance companies to cover \$50,000 per year in autism treatment for children 8 years and younger and \$20,000 per year for children ages 9 to 18. The bill is named after five-year-old Brandon Simonsen who lives in Billings. The new law goes into effect January 1, 2010.

**NEVADA – 11<sup>th</sup> State to Pass Autism Insurance Bill!** Governor Jim Gibbons signed an autism insurance bill into law May 29 and sent it to the governor for signature May 23.

[Assembly Bill 162](#) "requires certain policies of health insurance and health care plans to provide an option of coverage for screening for and treatment of autism, authorizing the Board of Psychological Examiners to license behavior analysts and assistant behavior analysts and to certify autism behavior interventionists."

**NEW JERSEY** Senate and Assembly committees advanced a bill May 18 that would require insurers to cover screening and therapies related to autism spectrum disorder.


**PENNSYLVANIA** Three new regional autism centers geared toward improving access to services, education, research, and training for families and professionals were unveiled April 20 to help the growing number of Pennsylvanians living with an autism spectrum disorder.

The centers, a primary recommendation of the Pennsylvania Autism Task Force commissioned in 2004, will improve regional access to quality services and interventions, provide information and support to families, train professionals in best practices and facilitate collaboration among providers of services throughout the commonwealth. [↪](#)

## Maine Considers Long-Term Care Reform

Maine legislators are considering a measure to reform the state's long-term care system. [LD 1078, "An Act To Strengthen Sustainable Long-term Supportive Services for Maine Citizens,"](#) requires the state's Department of Health and Human Services to develop a unified system of in-home and community support services, including self-directed care, for adults with long-term care needs who are eligible for services.

The bill is based on the following legislative findings:

- A. In-home and community support services have not been sufficiently available to many adults with long-term care needs;
- B. Many adults with long-term care needs are at risk of being or already have been placed in institutional settings, because in-home and community support services or funds to pay for these services have not been available to them;
- C. In some instances placement of adults with long-term care needs in institutional settings can result in emotional and social problems for these adults and their families;
- D. For many adults with long-term care needs, it is less costly for the State to provide in-home and community support services than it is to provide care in institutional settings;
- E. The majority of adults with long-term care needs have indicated a preference to remain in their own homes and in community settings rather than having their needs met in institutional settings; [emphasis is in bill itself]
- F. For many adults with long-term care needs and their families, the process to identify and secure appropriate services is confusing and difficult to navigate; and
- G. A sustainable system of long-term care to meet the needs of citizens must emphasize in-home and community support services that capitalize upon personal and family responsibility." 

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## Becoming a Person Centered System Report Released

[Becoming a Person Centered System](#) by Michael W. Smull, Mary Lou Bourne, and Helen Sanderson was just published and is now available at the NASDDDS website.

This report is the first in a series on a system change collaborative with state developmental disability agencies in Georgia, North Carolina, Oregon, South Dakota, Tennessee, and Virginia.

NASDDDS, Support Development Associates, and Virginia Commonwealth University respectively manage parts of the initiative.



The initiative is funded in part by The Department of Health and Human Services Centers for Medicare and Medicaid Services Real Choice Systems Change Person-Centered Planning Implementation Grant FY 2007 CFDA 93.779 Building Person-Centered Organizations: Fulfilling the Promise of Person-Centered Planning. 

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## RESEARCH DISCOVERIES

**Scientists Find Gene Link to Autism and Gastrointestinal Disorders.** [Medical researchers](#) have known for some time that children with autism have a much higher rate of gastrointestinal disorders than other children. They have also linked gastrointestinal disorders to behavioral problems. More recently, scientists have found a gene variant associated with both conditions.

[University of Southern California and Vanderbilt University](#) scientists identified a specific gene variant that links increased genetic risk for autism with gastrointestinal conditions.

Researchers analyzed medical history records from 214 families in the [Autism Genetic Resource Exchange](#). They found that a variant in the MET gene was associated with autism specifically in those families where an individual had co-occurring autism and a gastrointestinal condition.

The study, “Distinct Genetic Risk Based on Association of MET in Families with Co-occurring Autism and Gastrointestinal Conditions” by Daniel B. Campbell et al., appeared in the March issue of *Pediatrics*. Click [here](#) to read the abstract.

[Dr. Martha Herbert](#), a pediatric neurologist and a brain development researcher, applauds the discovery. “What they’ve shown is that [autism and gastrointestinal disorders] are co-occurring,” Dr Herbert says. “That’s a very welcome development, and these people should be commended for recognizing that autism doesn’t just affect the brain, it affects the whole person.”

She thinks that autism may result not from subtle differences in brain structure, but from body-wide dysfunction in cells. The MET gene may be one example: when the gene’s activity is disrupted, multiple body functions go wrong, including brain activity and digestive system function.

Dr. Herbert provided a keynote address for NASDDDS’ conference last year on autism, organized with the Autism Society of America. Her presentation, “New Medical & Biomedical Research and Implications for Services and Supports,” is available on our website by clicking [here](#).

She is a Pediatric Neurologist at the Massachusetts General Hospital of Harvard Medical School in Boston, a brain development researcher at the Harvard-MIT-MGH Martinos Center for Biomedical Imaging, and the Director of the TRANSCEND Research Program (Treatment Research And Neuroscience Evaluation of NeuroDevelopmental Disorders).



**New IQ Scoring Method Helps Reveal Potential of Kids with Fragile X.** [David Hessler](#), an associate professor of clinical psychiatry and a researcher at the UC Davis [M.I.N.D. Institute](#), and a team of collaborators devised a new system of scoring IQ tests taken by children with fragile X syndrome, a genetic disorder that causes intellectual disabilities, including autism.

“If this new method becomes widely available, we will be able to tell parents something more useful and more accurately diagnose and treat young children who are learning disabled,” said Hessler, a physician who cares for children at the M.I.N.D. Institute with fragile X syndrome.

According to Hessler, there is a lot of meaningful variability in the performance of these children on IQ tests. “We believe that this variability is important information about the relative strengths and weaknesses that these children have,” he said.

Details of the new method are described in the study, [“A solution to limitations of cognitive testing in children with intellectual disabilities: the case of fragile X syndrome,”](#) published last fall by the [Journal of Neurodevelopmental Disorders](#).



**New Drug to Treat Fragile X Evaluated.** Six out of 12 participants with Fragile X given a single dose of a new oral drug, fenobam, had calmer behavior, were less hyperactive, and experienced reduced anxiety. Results of the initial evaluation also showed there were no adverse side effects from the medication.

“Currently, there are no therapies on the market to treat cognitive deficits associated with Fragile X

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## RESEARCH DISCOVERIES continued from page 8...

syndrome,” said Rush University Medical Center pediatric neurologist and principal investigator of the study. Dr. Elizabeth Berry-Kravis. “This pilot study has identified the potential beneficial clinical effects of fenobam, but further research is needed.”

To read “A pilot open label, single dose trial of fenobam in adults with fragile X syndrome,” published in the *Journal of Medical Genetics*, [click here](#).



**California Rise in Autism: It’s Not Better Diagnosis, Researchers Say.** Researchers at the [UC Davis M.I.N.D. Institute](#) found that the seven- to eight-fold increase in the number children born in California with autism since 1990 cannot be explained by either changes in how the condition is diagnosed or counted -- and the trend shows no sign of abating.

Published in the January 2009 issue of the journal [Epidemiology](#), results from the study, “The Rise in Autism and the Role of Age at Diagnosis. Epidemiology” by Irva Hertz-Picciotto and Lora Delwiche, also suggest that research should shift from genetics to the host of chemicals and infectious microbes in the environment that are likely at the root of changes in the neurodevelopment of California’s children. The study was based on data from California’s Department of Developmental Services (DDS).

Check out the corresponding DDS study, [Autism Spectrum Disorders: Changes in the California Caseload: An Update June 1987-June 2007](#).

### **National Children’s Study Begins in NC and NY.**


The [National Institutes of Health](#) announced in January that the National Children’s Study will begin recruiting volunteers to take part in its comprehensive study of how genes and the environment interact to affect children’s health. The study will track the health and development of more than 100,000 children from before birth through to their 21st birthday.

NIH officials announced that the first phase of recruitment for the study will begin in [Duplin County, N.C.](#) and the [New York City borough of Queens](#).

“The principal benefit of a large scale, long-term study like the National Children’s Study is that it will uncover important health information at virtually every phase of life,” said Duane Alexander, MD, Director of NIH’s Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), one of a consortium of federal agencies implementing the study. “Initially, it will provide major insights into disorders of birth and infancy, such as preterm birth and its health consequences. Ultimately it will lead to a greater understanding of adult disorders, many of which are thought to be heavily influenced by early life exposures and events.”



### **ASA Launches Course on Autism and the Environment.**

The Autism Society of America is releasing its newest online course, [“Autism and the Environment 101.”](#) The introductory-level course was designed to give individuals with autism spectrum disorders, parents, other family members, physicians, educators or anyone affected by autism a general overview of the links between environmental toxins and autism. 

## RESOURCES

### **Person-Centered End-of-Life Planning and Care.**

Respecting the wishes and eliciting the decisions of individuals with developmental disabilities as they age and pass away involves sensitivity, respect, and careful planning. Gerontologist and person-centered practices specialist Leigh Ann Kingsbury created [People Planning Ahead: Communicating Healthcare and End-of-Life Wishes](#) for families and professionals to ensure that loved ones’ personal, cultural, and religious beliefs and preferences during times of chronic and terminal illness or severe disability are respected.

“I recommend this workbook to anyone and everyone who will have a say in how we will support people in their last days,” says Michael Smull, Chair of The Learning Community for Person Centered Practices. “I had the opportunity to make use of an early draft of *People Planning Ahead* with Belinda, a woman with intellectual disabilities who was dying of cancer. She was well known and loved by people inside and outside of the service system. Those who were supporting her wanted to help maintain the dignity and respect that she had fought for

(RESOURCES continued on page 10)

## RESOURCES continued from page 9...

and achieved all the way through the end of her life. Having a structured way to talk with her about her care and what to do with the things she loved helped us listen and helped Belinda to tell us what was important to her. It was not a way to avoid tears; it was a way to deal with difficult issues in a way that kept us respectful and kept Belinda feeling respected.”

To learn more about [People Planning Ahead](#), visit the [AAIDD bookstore](#). To find out more about training based on People Planning Ahead to help people make healthcare decisions, identify surrogate decision makers, and develop plans for care at end of life contact AAIDD at [books@aidd.org](mailto:books@aidd.org) or call (800) 424-3688. To contact the author Leigh Ann Kingsbury with other questions, at [leighlakingsbury@suddenlink.net](mailto:leighlakingsbury@suddenlink.net) or call (910) 297-3510.

**Disability Law Handbook.** The *Disability Law Handbook*, providing a broad overview of rights and obligations under federal disability laws, is now available online at [www.swdbtac.org/html/publications/dlh/index.html](http://www.swdbtac.org/html/publications/dlh/index.html). The book is also being translated into Spanish and will soon be available electronically.

### New Books on Religion and Disability.

(Special thanks to Bill Gaventa, Director of Community and Congregational Supports at the Elizabeth M. Boggs Center on Developmental Disabilities and Editor of the *Journal of Religion, Disability, and Health*, for providing this list — though the listing of these works does not necessarily imply endorsement.)

Shelly Christensen. [Jewish Community Guide to Inclusion of People with Disabilities](#). Minneapolis: Jewish Family and Children's Services, 2007.

Stanley Hauerwas and Jean Vanier. [Living Gently in a Violent World. The Prophetic Witness of Weakness](#). Downers Grove, IL: Intervarsity Press, 2008.

Stephanie Hubach. [Same Lake, Different Boat: Coming Alongside People Touched by Disability](#). Phillipsburg, NJ: P&R Publishing, 2006.

Wati Longchar and Gordon Cowans. *Disabled God Amidst Broken People: Doing Theology from Disability Perspective*. Manila: [Association for Theological Education in South East Asia](#), 2007.

Saul M. Olyan. [Disability in the Hebrew Bible: Interpreting Mental and Physical Differences](#). Cambridge: Cambridge University Press, 2008.

Hans Reinders. [Receiving the Gift of Friendship: Profound Disability, Theological Anthropology and Ethics](#).

Grand Rapids, MI: Eerdmans Publishing, 2008.

Tom Reynolds [Vulnerable Communion: A Theology of Disability and Hospitality](#) Grand Rapids, MI: Brazos Press, 2008.

Related resource: [Praying with Lior](#), a documentary about the religious journey of a young man with Down syndrome. See [www.prayingwithlior.com](http://www.prayingwithlior.com).

**Books for Dessert Book Club.** “Books for Dessert,” a book club for adults over 21 with intellectual disabilities is enjoying its fifth year of success. Hosted by the Port Washington Public Library in Washington state, the club brings people together to read books and stories of all kinds in adapted versions such as Mark Twain’s *The Prince and the Pauper* and Shirley Jackson’s *The Lottery*. If you are an organization or individual interested in replicating this program in your community, please contact Lee Fertitta at (516) 883-4400, Ext. 135, or email [fertitta@pwpl.org](mailto:fertitta@pwpl.org) for more information. The library is preparing a program guidebook which will be available soon.

### New FREE Web Browser for Children with Autism.

The ZAC (Zone for Autistic Children) browser is the first web browser developed specifically for children with autism, and autism spectrum disorders such as Asperger syndrome, pervasive developmental disorders (PDD), and PDD-NOS. The browser enables children to touch it, use it, play it, interact with it, and experience independence. ZAC is at [www.zacbrowser.com](http://www.zacbrowser.com).

### Report on Closing the North Dakota Developmental Center.

Dr. David Braddock’s report, *Closing the North Dakota Developmental Center: Issues, Implications, Guidelines*, is intended to stimulate discussion and further study by The Arc and other interested parties in North Dakota on the possible closure of the North Dakota Developmental Center at Grafton. Download the entire report [here](#).

**New Budget Allocation Website.** SAGE Resources, housed within the [Human Services Research Institute](#), is launching a new website at [www.sageresources.org](http://www.sageresources.org). “On this site we will focus on issues related to establishing budget allocations for people with developmental disabilities so that they can get the services they need,” explains HSRI Vice President John Agosta. “We expect that these allocations will be informed by systematic assessment of individual support needs. Primarily, we use the [Supports Intensity Scale](#) to provide essential information on individual needs. At the least, the resulting allocations should be sufficient for each person, fair to all and promote system efficiency.” ↪

## LITIGATION/LEGAL UPDATES

**U.S. SUPREME COURT Considers DD Determination of Death Row Prisoner.** The U.S. Supreme Court is considering the question of a state's ability to litigate a defendant's intellectual disability in a post-conviction Atkins hearing. In 2002, the U.S. Supreme Court in [Atkins v. Virginia](#) barred the execution of offenders with intellectual disability ("mental retardation"), but left it to the states to define "mental retardation."

Almost 10 years before the Atkins decision, the State of Ohio sentenced to death Michael Bies for the murder of a 10-year-old boy. At the penalty phase of his trial, Bies offered as mitigating evidence the testimony of a psychologist who explained that his IQ fell within the range of mild to borderline "mental retardation."

"Prosecutors in Ohio want a fresh shot at litigating the question of whether Mr. Bies is retarded," [The New York Times](#) said, noting: "It does not bode well for a death row inmate when his lawyer must spend the bulk of a Supreme Court argument fending off combative questions from two of the court's most liberal justices." See [Bobby v. Bies, No. 08-598](#).

Bie's defense attorney argued that the determination of mental retardation made in the penalty phase of the trial should preclude the state from litigating this question under the new standard set after Atkins.

Click [here](#) to access documents related to this case. Click [here](#) to read a summary of the arguments before the U.S. Supreme Court, written by a Stanford University law student.

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**AMERICAN BAR ASSOCIATION Addresses Guardians' Concerns.** The [Virginia Office of Protection and Advocacy](#) recently posted a response from the American Bar Association to a letter from the VOR on guardians' concerns.

See: [American Bar Association \(ABA\) Response to VOR Letter - Guardians of Individuals with Intellectual Disabilities \(04/16/09\)](#) and [VOR Letter to the ABA - Rights of Guardians of Individuals with Intellectual Disabilities \(01/09\)](#)

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**OLMSTEAD PLANS AND LAWSUITS.** The Center

for Personal Assistance Services (PAS) released a report on states' implementation of the 1999 U.S. Supreme Court Olmstead decision that people have the right to receive care in the most integrated, least restrictive setting appropriate.

The report provides tables outlining states' strategies to comply with this decision and summary of community integration lawsuits related to Olmstead.

A [clickable U.S. map](#) is also included, providing Olmstead plans and related lawsuits by state.

Report website: [pascenter.org/olmstead/index.php](http://pascenter.org/olmstead/index.php)  
Report [PDF](#) (179K, 16 pages)  
Table 1- State Olmstead plans [PDF](#)  
Table 2 - Olmstead-related lawsuits [PDF](#)

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**ALABAMA Wrongful Death Lawsuit.** A lawsuit was filed April 7 claiming that a 58-year-old Partlow Developmental Center resident died from neglect, [Tuscaloosa News](#) reported. Johnnie Mack Whitten, who was supposed to be under 24-hour observation, "suffered a traumatic brain [when] the night staff person assigned to Whitten left him unsupervised at various times on the night that he was injured and later altered timesheets to hide the fact that she left her post," the newspaper said, citing an October Centers for Medicare and Medicaid Services report.

The Alabama Disabilities Advocacy Program released an investigative report, [At What Cost: Partlow's Legacy of Shame](#), last December, calling for the closure of the developmental center.

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**ARIZONA Judges Say State Can Implement Cuts.** Arizona's State Court of Appeals said April 30 that the Department of Economic Security can implement budget cuts:

"Plaintiff Beneficiaries and those who care for the developmentally disabled understandably seek to ensure that services to that vulnerable population continue without interruption. We also recognize that the abrupt nature of the services suspensions and rate reductions the Division impose in February caused great alarm and dismay. Finally, we appreciate the difficulty of assembling and presenting evidence — on very short notice — to demonstrate

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facts to support the existence of serious legal questions as to whether the Division's decisions will cause the State to breach its obligations under federal law. We conclude, however, that the record before us at this time simply does not contain substantial evidence to support enjoining the Division's service suspensions or rate reductions."

To read the Court's ruling, click [here](#), (also see **CSR** April 2009).



### CALIFORNIA

**(1) Lawsuit Filed to Prevent Service Cuts.** The California Primary Care Association [filed a lawsuit](#) against the state of California April 29 to prevent critical Medi-Cal (Medicaid) benefits currently being provided by California's Federally Qualified Health Centers (FQHCs) and Rural Health Centers (RHCs) from being cut.

In February, Governor Arnold Schwarzenegger and the state legislature enacted a budget that eliminated, effective July 1, 2009, nine Medi-Cal "optional benefits," including adult dental, psychology, chiropractic, acupuncture, speech therapy, incontinence creams and washes, audiology, optometry, and podiatry services.

The lawsuit contends that the state of California has mischaracterized certain core FQHC/RHC services as optional benefits, and that the State must continue to reimburse FQHCs/RHCs for core services provided to Medi-Cal beneficiaries.

To learn more about the suit, click [here](#). To download the [Writ of Mandate](#), click [here](#).

**(2) Capitol People First Suit Settled.** California Superior Court Judge Robert Freedman approved a final [settlement agreement](#) for the seven-year-old **Capitol People First et al v. Department of Developmental Services et al.** lawsuit.

The settlement agreement includes the following:

"Subject to Legislative approval, DDS [Department of Developmental Services] will provide additional funds to each Regional Center to assist the Regional Center in arranging for a case worker to attend Individual Program Plan (IPP) meetings of

persons residing in Developmental Centers (DCs). "Regional Centers will provide information to persons living in certain large private facilities about possible living arrangements in smaller, community-based settings.

"DDS will provide training to DC staff about community living options.

"DDS will work with Disability Rights California and the State Council on Developmental Disabilities to provide information and training to class members about community living options.

"Regional Centers and DDS will continue to use the Community Placement Plan process to help class members move from the DC s to community settings.

"Regional Centers and DDS will develop new community programs and housing options.

The Settlement will remain in effect for three years. During this period, Disability Rights California, the attorneys for the Plaintiffs, will receive reports which will allow it to monitor the Defendants' performance under the Settlement Agreement."

For more information and background, go to [www.disabilityrightsca.org](http://www.disabilityrightsca.org).

**(3) Furloughs for State Workers.** Sacramento Superior Court Judge Patrick Marlette ordered state Controller John Chiang January 29 to implement a Schwarzenegger administration plan to furlough state workers two days a month, resulting in a 10% pay cut, [The Sacramento Bee](#) reported.

**(4) Parents Sue Kaiser P for Autism Services.** Two parents in the Bay Area filed a class action lawsuit against Kaiser Permanente February 11 to compel Kaiser to provide services for their respective children, [The San Francisco Chronicle](#) reported.



### GEORGIA Court in Medicaid Suit Says Doctors Do Not Have Final Say.

"A private physician's word on medical necessity is not dispositive," the 11th U.S. Circuit Court of Appeals said April 24 in regard to a case where personal care hours for a girl with disabilities were reduced from 94 hours a week to 84.

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"[I]t does not follow that the state is wholly excluded from the process of determining what treatment is necessary. Instead, both the state and [the girl's] physician have roles in determining what medical measures are necessary to "correct or ameliorate" [the girl's] medical conditions."

To read the [Moore vs. Medows](#) decision, click [here](#).



**IDAHO Judge Blocks Cuts.** U.S. District Judge Justin Quackenbush issued a temporary restraining order April 28 against Idaho's Department of Health and Welfare to block a 55% cut to payments to service agencies, [Idaho Business News](#) reported.



**MASSACHUSETTS U.S. Supreme Court Declines to Hear Fernald Case.** The U.S. Supreme Court declined April 6 to hear an appeal of the closing order for the Fernald Development Center.



**MISSOURI County Settles Lawsuit over Closing of Institution.** Madison County in Southeast Missouri, population ~12,000, reached a settlement in a lawsuit over its decision to close its "Sheltered Care Home" for individuals with developmental disabilities or mental illness, [KWMU/NPR](#) reported.



**NEBRASKA DC Residents Sue State.** Guardians of six Beatrice Developmental Center residents transferred to other facilities are suing the State of Nebraska saying the state violated their civil rights by not improving conditions in the long-troubled facility. "Plaintiffs say that in defiance of warnings from the Justice Department, the state merely removes residents with serious problems from the facility against their will, rather than address problems at the center," the [Courthouse News Service](#) reported May 5.



**OHIO EPSDT Lawsuit for Autism Services.** The Ohio Legal Rights Service (OLRS) filed a [brief](#) in the U.S. Court of Appeals for the Sixth Circuit January 12 in a case on behalf of children with

autism. The brief asks the Court to uphold the preliminary injunction order and to remand the case for trial in the district court.

The lawsuit, ***Parents' League for Effective Autism Services (PLEAS) v. Helen Jones-Kelley***, Director of the Ohio Department of Job and Family Services, filed a year ago, stems from complaints OLRS received from families of children with autism regarding the state's "narrow definition of rehabilitative services" in its Medicaid Early, Periodic, Screening, Diagnostic, and Treatment (EPSDT) program, an OLRS announcement said.

Click [here](#) for more information and [updates](#).



**PENNSYLVANIA Judge Says Sperm Bank Liable for Child's Fragile X.** In an unprecedented decision, Senior U.S. District Judge Thomas N. O'Neill Jr. said a 13-year-old girl with an intellectual disability in Pennsylvania can sue a sperm bank in New York under product liability laws for "failing to detect that a sperm donor had a genetic defect," [The Legal Intelligencer](#) reported April 2.



**TEXAS Judge Sentences Teen with DD 100 Years in Prison.** An 18-year-old with an IQ of 47 who pleaded guilty to sexually molesting a six-year-old boy was sentenced to 100 years in prison April 7 by Judge Eric Clifford of the 6th District Court in Lamar County, Texas, [The Los Angeles Times](#) reported.

Aaron Hart sat silent, shackled in his chair in the courtroom while his appellate attorney David Pearson, argued that "the teenager had received ineffective legal assistance because his trial attorney had failed to present any expert testimony about Hart's diminished mental functioning or his ability to comprehend the charges against him," the newspaper said.

"This case cried out for a mental health evaluation, to explain this disability to the judge and jury," Pearson told Clifford. "One of the features of people with this kind of mental retardation is they cannot appreciate degrees of wrongfulness." ☹

## Virginia Boots Out “R” Word

Virginia's General Assembly recently passed legislation to change the name of the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) to the Department of Behavioral Health and Developmental Services (BHDS). The new name eliminates the pejorative “R” word, more broadly reflecting the department's mission, and allows flexibility to grow into other service areas, like autism, a departmental announcement said. The name change will be effective July 1, 2009.

Spearheading support for this legislation was self-advocate Jill Egle, Leadership Intern and Co-Executive Director for the [Arc of Northern Virginia](#) where she has worked for two years. “My focus goals in 2008 [was] to get rid of the R word, increase Arc membership, and fundraising special events,” she said.

To read the name change measures, click on [SB 1117](#) and [HB 2300](#).

During the 2008 Session, the General Assembly passed a bill to replace the term “mental retardation” with “intellectual disabilities” throughout the entire Code of Virginia. The bill was brought forward by The Arc of Northern Virginia and passed with a reenactment clause that required the 2009 General Assembly to vote on and pass the bill again. Afterwards, it was determined that replacing the term throughout the entire Code would jeopardize federal funding for programs that at this time must contain the words “mental retardation.” The 2009 bill only changes DMHMRSAS' name as a first step to updating the Code language.

Last summer, DMHRMSAS conducted surveys for staff and stakeholders to submit opinions on options for the department's new name. The nearly 1,500 responses reflected support for renaming DMHRMSAS the Department of Behavioral Health and Developmental Services (BHDS). The cost of the name change will be absorbed by the department. ☺

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Additional Information will be posted on the [NASDDDS website](#) as it becomes available.