

**STEM CELL
THERAPY:
NEW HOPE**

**DISABILITY FUNDS
IN THE
STIMULUS PLAN**

**GROUP ACTS TO
PROTEST
LEWIS AWARD**

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Issue 1

The Founder and Editor of *The Disability Rag*,
Mary Johnson
of Louisville, Ky.

“Like many people who are involved in ventures that fuel movements, I really was too busy to think much about *The Rag’s* “role” in the movement. Looking back from my distance today, I am aware that there was an ongoing tension between activists who wanted us to be more activist and my instincts to be (the voice of) “journalism” -- reporting but not participating actively. I don’t know if that was a correct choice or not.”



**GIL YILDIZ
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FELLED BY BULLET,
NOW HE LIFTS UP
OTHERS**

**WORLD INSTITUTE
ON DISABILITY
AT 25**

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Commentary**At the Oscars, Group Acts To Protest
Jerry Lewis Award***By Janine Bertram Kemp*

About 50 protesters from the disability group The Trouble with Jerry took to the streets of Los Angeles for the three days leading up to the Academy Awards. Other protests were held in Rochester, New York City and Denver on the day of the awards.

At this year's Oscars ceremonies, the Academy of Motion Picture Arts and Sciences (AMPAS) presented the Jean Hersholt Humanitarian Award to Jerry Lewis. He was called a humanitarian because of the money he has raised for the Muscular Dystrophy Association (MDA) through an annual Labor Day telethon.

To the disability rights community, it was liked getting slapped in the face twice.

First, Lewis has spent 40 years using pity and paternalism to raise funds for the MDA. That telethon model degrades people with disabilities and is, in fact, illegal in Great Britain for just that reason. To people with disabilities, of which I am one, Lewis' fund-raising has come at the cost of our dignity and societal inclusion.

Second is the issue of Lewis' own smears against people with disabilities. He is unapologetic about his numerous anti-disability comments. He has said, for example, "If I were in a wheelchair, I'd be half a person" and "I'd shoot myself." Another choice morsel from Lewis' ableist repertoire was, "You don't want to be pitied because you're a cripple in a wheelchair, stay in your house!"

Writer and Chicago activist Mike Ervin is on the steering committee for The Trouble with Jerry. A former member of "Jerry's Kids," he has been protesting

Lewis and the MDA charity model since 1991. Ervin has said that Lewis and the telethon are the primary forces perpetuating destructive, outdated views of people with disabilities.

"It devalues and dehumanizes people with disabilities by suggesting we can be worthy contributors only if we first shed our disabilities," Ervin wrote. "It gives people permission to avoid addressing the daunting task of creating an inclusive society if they simply make an annual contribution to Jerry."

The Los Angeles protest included writers, activists, artists, lawyers and media mavens. Thomas Webb of Washington, D.C., heard of the gathering and hopped on a plane to Hollywood. Lilibeth Navarro, executive director of Communities Actively Living Independent and Free (CALIF), participated along with her staff. Of the many centers for independent living in and around L.A., it was CALIF that opened hearts and doors to support The Trouble with Jerry. Noted disability rights photojournalist Tom Olin was there, and Denver poet and activist Laura Hershey was the lead organizer.

Upon hearing the names of those attending, Josie Byzek of New Mobility magazine said, "Ah, the luminaries of the disability movement." In a sense, she was right, but the majority of the protesters were less well-known, people who used their own money to travel and donated still more for printing and supplies. For many, including those who had recently seen significant loss of income, it

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**THIS DAY IN
DISABILITY
HISTORY**

January 4th, 1809 – Louis Braille is born. Braille became blind at the age of 3, after an accident and subsequent infection. At age 10, he earned a scholarship to the Royal Institution for Blind Youth in Paris, one of the first schools for blind individuals. At 11, after being introduced to a form of communication that used 12 raised dots, Braille began devising his own form of communication, which became known as Braille. After finishing the basic structure of Braille at age 15, he later expanded the system to include a way to notate music and do mathematics. He also worked with a contemporary to develop the machine Braille is typed on.

January 6th, 1969 – Abuse is uncovered at New York's Willowbrook State School, an institution for students with severe physical and mental impairments. Several local Staten Island newspapers wrote about deplorable conditions for residents of the school, including overcrowding, inadequate sanitary facilities, and physical and sexual abuse of residents by members of the school's staff. These abuses were exposed after it was discovered students were being used for hepatitis studies without the knowledge of their parents. The outcry of parents and elected officials led to broad changes in the way people with intellectual and physical disabilities were cared for, by increasing parent advocacy, mainstreaming students with disabilities, and utilizing community-based supports. The publicity generated by the case was a major contributing factor to the passage of a federal law, called the Civil Rights of Institutionalized Persons Act of 1980.

January 8th, 1942 – Renowned theoretical physicist Stephen Hawking is born in the midst of the bombing of London during World War II. After receiving his B.A. at Oxford University in 1962, Hawking enrolled at Trinity Hall, Cambridge, where he engaged in the study of theoretical astronomy and cosmology. He is known for his contributions to the fields of cosmology and quantum gravity, especially in the context of black holes. Almost as soon as he arrived at Cambridge, he started developing symptoms of amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease), a type of motor neuron disease that would rob him of almost all neuromuscular control. After earning his Ph.D., Hawking was elected one of the youngest Fellows of the Royal Society in 1974, was created a Commander of the Order of the British Empire in 1982, and became a Companion of Honour in 1989. Hawking's achievements were made despite the increasing paralysis caused by ALS. In 1985, he caught pneumonia and had to have a tracheotomy, which rendered him unable to speak. A Cambridge scientist built a device that enables Hawking to write onto a computer with small movements of his body and then speak what he has written with a voice synthesizer.

January 13th, 1966 – Actor Patrick Dempsey is born in Lewiston, Maine, the youngest of three children born to Amanda and William Dempsey, an insurance agent. Patrick was diagnosed with dyslexia at age 12 and must memorize all his lines for stage and screen. Dempsey starred in teen romances such as "Can't Buy Me Love" and "Loverboy" and currently is Dr. Derek Shepherd in the TV drama "Grey's

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CoverStory

Mary Johnson: 'Write' Stuff for the Disability Movement

By Mike Ervin

In the early 1980s I was fresh out of college, a restless youth eager to enjoy life in the big city. But public transit was not wheelchair accessible; neither was much of the infrastructure.

Somehow I ended up on the mailing list of *The Disability Rag*. It was a fiery magazine written by other gimps like me. They wrote about the isolation I felt. They, too, knew how it felt and were ticked off about it like I was. They spelled out the causes of and remedies for our segregation in clear, sharp, political terms. *The Disability Rag* was bold, brash and inspiring. Like others, it turned me into an activist.

The founder and editor was Mary Johnson of Louisville, Ky. But this woman, whose publication articulated the disability experience with unprecedented authenticity, had no disability herself. As a child and young adult, she says, "I really had no interactions to speak of with disabled people other than the typical ones -- you'd see a man in a wheelchair and ask your mom and she'd say, 'Don't stare' -- things like that."

The Disability Rag chronicled and fueled the emerging disability rights and independent living movements.

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The first edition came out in January 1980. It ceased publication in 1996 but started again as the *Ragged Edge* in January 1997. A Web site, www.raggededgemagazine.com, was launched at the same time. The Web site still exists, but no new content has been added since 2006. The print version of *Ragged Edge* ceased publication in 2004. The Advocado Press (www.advocadopress.org), which published *The Disability Rag* and *Ragged Edge*, still sells a few books written by Johnson and others.

These days, Johnson helps her husband, Robin Garr, operate his food and wine Web sites.

"Whether I will get back into disability rights is a big unknown for me now," she says. "I do still have some things I want to say -- maybe in a book someday -- but that will have to wait for later. Unfortunately, or fortunately, there will always be work to do in writing about disability rights, should I be able to return to that!"

In a recent interview, Johnson discussed the influences in her life, how *The Disability Rag* came into being and the role it played in shaping the culture.

Independence Today: What occurrences in your life helped shape your political and disability consciousness?

Mary Johnson: I came of age in the 1960s, and so I was attuned to civil rights, women's rights, etc. I went to a small local college and wasn't really an activist in any way. I got a degree in English, worked for a time doing reporting for weekly papers, did some PR work for nonprofits.

My involvement in disability rights started when a friend asked me if I'd be willing to serve on the board of a newly formed group. This was in the early 1970s, and as you know, nonprofits often want people with

PR backgrounds on their boards. I said OK but didn't really know what I was getting into. The director, a woman with CP, was starting the first "consumer group" of disabled people in Louisville. I got a real education from her. She explained to me that disabled people -- "handicapped adults" was the term used back then -- had a right to transportation, housing, etc. It was like the proverbial light bulb going off, and I was hooked. I was particularly appalled that nobody seemed aware of any of this, and since I wanted really to be a journalist -- and hoped someday to land a good job on a newspaper -- I guess I got into investigating it like a journalist would.

IT: How did this lead to *The Rag*?

MJ: Several years later, I was still involved in what we were just starting to call "disability rights" in Louisville. Our group had gotten VISTA (Volunteers in Service to America) volunteers and was doing some community organizing, but it was clear that we weren't reaching enough people. As is even the case now, the big problem was transportation. People couldn't get to organizing meetings! Our VISTAs were really into "consciousness raising" as a concept, so I got the idea of putting out some sort of a publication, and we called it *The Disability Rag*. It was just local; it was just one 11x17 sheet folded. But people really took to it! After a couple of years we made it bigger, we incorporated an organization -- The Advocado Press -- to publish it. Cass Irvin, one of the incorporators, decided it should be circulated nationally and spearheaded that effort. That effort, which I have to admit I wasn't too

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interested in, was a big success by the measure of the day. People seemed to want it, and it became popular in activist circles. I think the time was right. It was just at the time of the grass-roots disability rights movement taking off. A couple of years later, ADAPT started and moved to the national stage and *The Rag* was there to report on all this.

IT: Was it always a financial struggle?

MJ: Yes, it was always. We weren't in it for the money, and nobody on our board was really that good at fundraising. The amazing thing was that we got as much money as we did -- the vast bulk of it from readers who didn't have all that much money. People paid for their subscriptions and answered our pleas for donations. At its height in the late 1980s and early 1990s, it had several paid staff.

IT: And later, in 1999, there was the famous May Media Meeting, at which disability journalists gathered in Louisville. This led to the creation of the Mediatalk listserv, which writers and activists still use today.

MJ: That plan was hatched in early 1998, and the Advocado Press board OK'd it. We announced it in *The Rag* in the fall of 1998, I think, and we ended up with about 50 participants, as I recall. There was no seed money; everything was paid for by registrations!

Mediatalk was a way to continue what had been started at the May Media Meeting. It started as a Yahoo group. I set it up in the fall of '99, I believe. It went great guns for a while, but like many things sort of became more of an information-sharing listserv than an activist organizing site, which is what I think some folks wanted.

IT: What role did *The Rag* and *Ragged Edge* play in the disability rights and independent living movements?

MJ: Like many people who are involved in ventures that fuel movements, I really was too busy to think much about *The Rag's* "role" in the movement. Looking back from my distance today, I am aware that there was an ongoing tension between activists who wanted us to be more activist and my instincts to be (the voice of) "journalism" -- reporting but not participating actively. I don't know if that was a correct choice or not.

IT: How well do activists understand and successfully use the media today as opposed to back then?

MJ: Of course the media landscape is so different today. Blogs are clearly doing what print media did in the '80s and '90s in the movement. As always, though, core problems remain. Too few people associate, identify or are aware of even the concept of disability rights, much

less paying attention to or understanding issues. My thoughts about the movement and media were really laid out in my 2003 book "Make Them Go Away." I still do not believe that the disability rights movement values or understands the role of the media or is particularly sophisticated in knowing how to use it. I more think this is a problem of lack of interest than lack of skill. I think the movement has always seen its focus on things like getting laws passed and doesn't seem fully aware of how to use mass media to change understanding -- or maybe it just seems to be too big of a job. And perhaps it is too big of a job. Consciousness takes an immense effort to change, and just like our VISTAs believed, what's really needed still is what we used to call consciousness raising.

Mike Ervin is a freelance writer and member of American Disabled for Attendant Programs Today, a group that works for the civil rights of people with disabilities.

For Those with Mental Illness, Access to Care Part of Cure
By Brenda Brown-Grooms

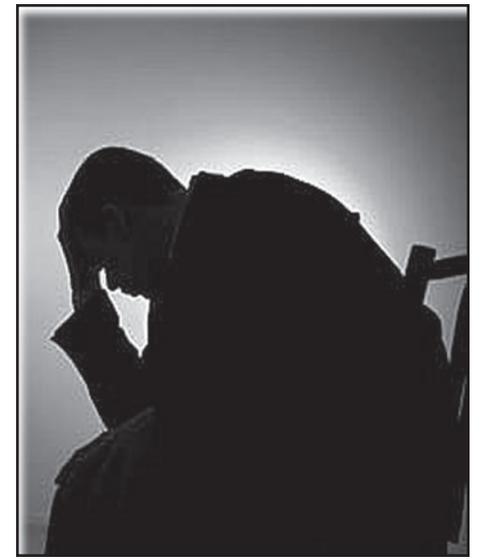
According to the last census, there are 306 million people living in the United States. Twenty-two percent of the total adult population (67,320,000) suffers from a diagnosable mental disorder in a given year. Eighteen million adults in the U.S. have severe mental illness, while another 43 million have less severe symptoms.

According to the Web site HealthyPlace.com, mental illness is a disease that causes mild to severe disturbances in thinking, perception and behavior. The site recommends that if the disturbances significantly impair a person's ability to cope with life's ordinary demands and routine, then he or she should immediately seek proper treatment with a mental health professional.

According to MentalHealth.com, 47 million Americans are without health insurance and 36 million live in poverty.

The five major categories of mental illness are anxiety disorders, mood disorders, schizophrenia, dementias and eating disorders.

Anxiety disorders are the most common forms of mental illness. The three main types of anxiety disorders are phobias (extreme fear or dread caused by a specific



Depression

object or situation), panic disorders (sudden, extreme fear or dread for no apparent reason with symptoms similar to a heart attack) and obsessive-compulsive disorders (sufferers try to cope with anxiety by repeating words or phrases or engaging in repetitive, ritualistic behavior, such as constant hand washing).

People with mood disorders (depression and bipolar disorder or manic depression) may display mood swings (extreme sadness or elation), sleep and eating disturbances, and marked changes in activity or energy levels. Suicide is a concern for a person diagnosed with a mood disorder.

Schizophrenia, believed to be caused by chemical imbalances in the brain, is a serious disorder that affects an individual's thinking, feeling and actions. Symptoms include hallucinations, delusions, withdrawal, incoherent speech and impaired reasoning.

Dementia, unlike Alzheimer's (a kind of dementia), does not cause death. It leads to loss of mental functioning, memory loss and a decline in intellectual and physical skills.

Those with eating disorders, such as anorexia

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Peter Kahrman: Felled by Bullet, Now He Lifts Up Others

By Amy Halloran

Peter Kahrman is a very open person; he made an interviewer laugh immediately when he spoke to her on the phone. In the course of getting to know him and some of the traumas that shape, but don't define, his life, one wonders if his openness was related to his brain injury. But the bullet that entered his brain is not necessarily responsible for his wide embrace of the world.

"It is not uncommon at all that people with frontal-lobe damage become disinhibited," said Kahrman, who lives with his three dogs in a countrylike setting west of Albany, N.Y. "There's no filter. In my case, I've always been this open, and I'm not entirely sure why."

Kahrman, who is in his mid-50s, was 30 when he was shot at close range in 1984. He was on his way to work in Brooklyn, N.Y., and it was dark. His brain suffered trauma not only from the bullet, but also from his head striking the ground when he fell.

Doctors decided not to remove the bullet because doing so would have caused more damage to the brain. Despite the incident, Kahrman was not diagnosed with traumatic brain injury (TBI) until almost a decade later.

"The symptoms I would later attribute to the brain injury I would think of as psychological," Kahrman said when asked to describe how he was changed. "The frontal lobe, the part of the brain that manages emotion -- when I was rested the brain could successfully compensate; when I was tired the brain couldn't compensate anymore. In brain injury,

when people become fatigued, the symptoms become very amplified."

The same thing happens without brain damage, he noted. People who are weary have less patience and a shorter fuse. Kids get obstinate. Parents get grumpy. Of course, Kahrman's challenges are not limited to grumpiness.

"For me there's pretty much a chronic struggle with fear," he said. "People call it anxiety. I choose the word that motivates me most to fight it. I'd rather get in a fight with fear." This motivation is key to understanding Kahrman, and it is the tool he gives others to use. The tool is a philosophy he developed called "Life Growth."

The seed of Life Growth came in a phone call from a longtime friend, a former Marine and a Vietnam veteran who was awarded the Bronze Star.

"You control it, or it controls you," Michael Sulsona said to Kahrman while he was hospitalized in 1984. Sulsona lost his legs in Vietnam and had been delivered Last Rites (now known as Anointing of the Sick) three times, so Kahrman knew that Sulsona understood adversity. While he trusted the words his friend gave him, he didn't apply them right away. That took some time and another violent incident: In 1985 Kahrman was held up at gunpoint, and he shut down. He wouldn't leave his apartment. Friends and neighbors brought him food and eventually helped him get counseling.

"When I was in seclusion, Michael's statement led me to what we call the Life Growth breakthrough," Kahrman said. "It became a standoff between me and fear."

The dynamics of this approach are simple. Kahrman draws it as two circles divided by a bar. The circles are a person, and his or her goal. The bar is the obstacle. For Kahrman, his fear got in his way of his goal, of leaving the house. Suffering from post-traumatic stress disorder, he continues to have difficulty with this basic activity. But by separating himself from his dual diagnoses of PTSD and TBI, Kahrman uses a logical device to handle his issues.

The Life Growth model was much in evidence at a recent meeting of a support group Kahrman leads. In Albany, about 10 to 15 people meet weekly to discuss their current challenges. The group operates under the auspices of the Brain Injury Association of New York State (BIANYS), of which Kahrman serves on the board. The group is open to anyone but focuses on people living with traumatic brain injury and the people who love and care for them.

Kahrman was late to the meeting. People drew two circles and a bar on the chalkboard; the circles were labeled Kahrman and Late. A question mark was drawn on the bar. What was keeping him from achieving his goal? The group was lighthearted, and some members eventually began the meeting without him by reading a creed that promises personal safety within the confines of the meeting. (The creed was reread following a break to reiterate the importance of safety.)

People introduced themselves. Some just said their names. Others detailed their history with brain injury and what they were facing that day, that week. Even before Kahrman arrived, people seemed supportive of each other, listening intently as they shared feelings and



Peter Kahrman

stories: about grief over having lost a version of themselves, the constant struggle to convince others that an invisible injury has effects, and their memory troubles.

Once Kahrman arrived, the affection for him was obvious. The atmosphere grew jovial again, and Kahrman was quite willing to poke fun and be poked fun at, too, as he settled in to a place at the table.

"When it comes to brain injury," Kahrman said, pulling a model brain from a bag, "it's all in your head."

This statement drew knowing laughs. Kahrman pointed to areas on the brain and described some of the functions they cover. He stood and erased the diagram on the chalkboard and redrew the same basic shapes, labeling the circle on the left "person," the bar in the middle "blockage," and the circle on the right "opening up."

"If you don't talk about what's going on, you don't get the help you deserve," Kahrman said. He looked people in the eye and repeated his words. The humor was gone from the room, but the sense of openness, of safety, remained.

Kahrman gently nudged people to talk about themselves. Some people

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Stem Cell Therapy Showing New Promise

By Mike Reynolds

When Barack Obama was a candidate for president, he promised to reverse policy on stem cell therapies, specifically embryonic stem cell treatments.

Since 2001, the Bush administration has limited researchers to the existing stem cells that were currently being used. The National Institutes of Health have maintained that there are currently more than 60 lines available for research, but several scientists dispute that figure, claiming that only 21 lines are available. It is thought that many of the other stem cell lines may be contaminated with host or other DNA signatures that would make research futile.

On January 23rd, the U.S. Food and Drug Administration approved the plans of Geron Corp., a California-based company, to conduct trials on people with spinal cord injuries, using embryonic stem cells that were actually part of the H1 stem cell line -- cells derived before August 2001 and thus eligible for federal funding under current law. When President Obama lifts current federal funding restrictions, as expected, the therapies that result may provide significant benefits for a number of disabilities, including spinal cord injuries. The reality is that stem cell therapies have been used for more than three decades in the treatment of several types of disabilities, including various forms of blood cancers.

Leukemia and multiple myeloma are two of several types of blood cancers that use stem cell therapy (SCT) as a mainstream method of bringing a cancer under control. The major benefit of SCT versus current chemotherapy regimens is

that most chemotherapy will kill cancer cells but also will kill the stem cells within the bone marrow, making it more difficult for the host body to continue to produce new, healthy blood products and cells.

In SCT, adult stem cells are withdrawn from the patient. The cells are then given a combination of chemotherapy or radiation to kill any cancer and reinfused into the patient. Upon reinfusion, a patient will likely be kept in a hospital setting for up to six weeks to ensure the transplant takes and he does not develop any infections because of a weakened immune system as a result of the transplant. Often an infection will occur, but because SCT has been done for nearly 30 years, standard measures exist for dealing with complications.

Another treatment that received media coverage in 2008 was a procedure that used umbilical cord blood to treat a 2-year-old with symptoms that appeared to suggest cerebral palsy. In March of that year, the television show "Today" reported that the infusion of stem cells that were obtained from the tot's cord blood reversed some symptoms that presented as brain damage. But the doctor who performed the transplant, Joanne Kurtzberg, a prominent researcher at Duke University Medical Center with a background in childhood blood cancers, said it was "far too early" to read anything into the results.

Although Kurtzberg may be unconvinced, the case of Dallas Hextell, the child diagnosed with cerebral palsy, provides some interesting and unique glimpses of how the

treatment of a disorder with neural involvement may look if experiments like those conducted at Geron eventually show even moderate success. While some of the footage in the "Today" segment looked convincing, it will be far more telling to see if any neurological deficiencies are present when the child reaches age 5 or 10.

Another study at the Duke medical center has found that an umbilical cord blood transplant performed on child patients can be successful even if taken from an unmatched donor. Researchers at Duke have said they believe the procedure may be especially useful for patients in minority communities, where finding a bone marrow match is often difficult.

In other areas of the world, stem cell treatments are already restoring vision to people who are blind. In a protocol cited by an October 2004 New Scientist study, retinal cells derived from embryonic stem cells were successful in providing improved vision. Vision improvement, however, sometimes took as long as two years. The reported success rate is between 25 and 70 percent.

As SCT enters a new phase in which it likely will become a mainstream research topic in the United States, it may bring about a host of new treatments for a wide variety of disabilities. Most people, however, are unaware that stem cell therapy often takes years to realize positive results.

For certain forms of cancer, including multiple myeloma, it has provided several more years of living and a quality of life that was unimagined in the past. But SCT is not a complete cure. No doctor can, with any certainty, make valid claims about SCT's effect on mobility or neural control as it relates to an individual with a spinal cord injury.

SCT, however, may grant people with disabilities who cannot travel to China -- whose government has allowed embryonic stem cell treatments for nearly a decade -- better access to treatments that may help with neurological issues. That also will create a new way of looking at how all sorts of disabilities, from cerebral palsy to diabetes, are treated.

SCT shows promise that it will broaden the options available to any patient who is dealing with a disability. For more information, go to: <http://news.bbc.co.uk/2/hi/health/7847450.stm>.

Note: The author has a relative who underwent a stem cell treatment related to a blood cancer in December 2004.

Mike Reynolds is a freelance writer and short movies producer.

Employment Status for Persons with Disabilities Released

In June 2008, questions were added to the Current Population Survey (CPS) to identify persons with disabilities (PWDs) in the civilian noninstitutional population age 16 and older.

The addition of these questions allowed the BLS (Bureau of Labor Statistics) to begin releasing monthly labor force data from the CPS for persons with disabilities. The data collection is sponsored by the Department of Labor's Office of Disability Employment Policy. Publication of CPS disability data began in February 2009 with the issuance of labor force data for January 2009. Explanatory materials are available on the "frequently asked questions" page. These materials provide

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information on comparisons with other data sources, variability of the data, and the types of data available.

In February 2009, the unemployment rate of persons with disabilities was 14.0 percent, compared with 8.7 percent for persons with no disability, not seasonally adjusted. The employment-population ratio for PWDs was 19.8 percent, compared with 64.8 percent for persons with no disability.

<http://www.bls.gov/cps/cpsdisability.htm>

Commentary

College Students with Disabilities Should Learn Their History

By Deborah Kendrick

When I was a senior in high school, I spent a little time reviewing college catalogs and making applications. That doesn't sound like much more than de rigueur, right? But let me explain a little of the extraordinary context in which those ordinary circumstances reside.

First, no one in my extended family had ever graduated high school, so college was something of a foreign idea.

Second, as the only blind student in a large public high school, I didn't exactly know how to go about researching institutions of higher learning. This was the late 1960s, after all, so there was no Internet. There were no scanners or reading machines. There weren't even any books on cassette that I could borrow from the library.

So, somehow, I zeroed in on the fact that I wanted to go to a small, private college. Somehow, I learned enough of about three of them to decide I liked them. And, somehow, I got people to fill in the applications for me.

Imagine my glee when my top choice accepted me! I hadn't yet begun to navigate the whole sea of who is going to pay for this and how, so I was in a state of bliss. Then my guidance counselor called me in to her office and said we needed to have a meeting with my parents.

The college, it turned out, was a tad conflicted about accepting a blind student. Let me repeat: This was the late Sixties. There was no disability rights movement in Toledo, Ohio. I didn't know anyone else with any kind of disability and, saddest of all, experience had taught me that the only way to be accepted and popular was to minimize my differences in every way possible, even if it meant doing things in ways that were 10 times more difficult than they needed to be or just missing out on experiences altogether.

There were several discussions and a meeting of my parents, me and all the powers that mattered at my college of choice. They had so many questions. Could I take physical education? (My high school had

Employment status of the civilian non-institutional population by sex, age, and disability status, not seasonally adjusted

(Numbers in thousands)

Employment status, sex, and age TOTAL, 16 years and over	Persons with a disability		Persons with no disability	
	Jan. 2009	Feb. 2009	Jan. 2009	Feb. 2009
Civilian non-institutional population	26,804	26,738	207,934	208,175
Civilian labor force	6,184	6,141	147,261	147,663
Percent of population in labor force	23.1	23.0	70.8	70.9
Employment-population ratio	20.0	19.8	65.0	64.8
Unemployed	816	859	12,193	12,840
Unemployment rate	13.2	14.0	8.3	8.7
Not in labor force	20,620	20,596	60,673	60,512
Both sexes, 65 years and over				
Civilian labor force	860	806	5,643	5,594
% of population in labor force	7.2	6.8	21.9	21.6
Employed	826	748	5,304	5,218
Employment-population ratio	6.9	6.3	20.6	20.2
Unemployed	34	57	339	376
Unemployment rate	3.9	7.1	6.0	6.7

centered its phys ed program on gymnastics, and I had done well.) That concern was crossed off the problem list.

How would I do in a science lab? Physiology had been my favorite subject after literature in high school, so I waxed enthusiastic about the skeleton, other models, working with a partner. We had made it work.

Foreign language? No problemo.

The bottom line was this: If I agreed to ask for no special favors (today we say accommodations) and, heaven forbid, didn't balk at meeting any of the required course requirements, I could come to school.

As inequitable as that bargain sounds today, I was elated! It was a definite deal. In the fall, I would go off to college — just like every other high school senior I knew.

I hired students to read for me. I talked to professors about my need to have a separate room where I could bring another student to read my tests to me. I schlepped probably a 30-pound "portable" Royal typewriter across campus to type my answers to said examinations. I schlepped another heavy piece of machinery, my reel-to-reel tape recorder, to other dorms or classroom buildings when I wanted students to record whatever they were reading to me. In the library, staff

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Center Director Yildiz 'Homes In' on Success

By Amy Halloran

Gil Yildiz is the executive director at the Independent Living Resource Center in Albuquerque, N.M. Born in Turkey, she was raised in New York City and lived there until she took her current position, more than nine years ago. She met her husband in Turkey. Both Gil and her husband had childhood polio.

Between Turkey, New York and New Mexico, her life has been a parade of landscapes, and her days are chock-a-block with paid work, advocacy efforts and family life. She is raising her two sons, aged 19 and 16, alone; her husband died two years ago. Pinning this busy woman down for a phone date was tricky, but once on the line, she was focused on the interview. Such focus and follow-through has likely contributed to the success of the endeavors she described.

"I've been in the independent living-disability rights field for over 25 years or so," said Yildiz, who started out at the Brooklyn Center for Independence in the early 1980s in a job she "thoroughly enjoyed," a housing counselor and advocate. "I didn't know that independent living or disability rights was going to be my career path but was really drawn into it when I first walked into that center in Brooklyn."

When asked how the triple challenges of her gender, ability and religion (Yildiz is Muslim) influence her outlook, she didn't have a set response.

"My parents were a big influence -- especially my dad," she said. "Just to demystify some of the stereotypes: It didn't matter that I was a person with a disability, now a woman, but then a girl growing

up. I didn't get treated any differently in terms of being held back as a woman and being Muslim. The expectation was that I would excel, especially from my dad."

And excel she has. She primarily discussed her work in New Mexico, but when listing her biggest accomplishments, none of it came across as boastful; she just seemed proud of the outcomes of her work.

"Money Follows the Person was the most successful legislative advocacy I have been involved in directly in New Mexico," Yildiz said, quick to share credit with her partner in the effort, Sherry Watson, former director of the San Juan Center for Independence in the Four Corners area of New Mexico.

"We wrote the bill, we worked with legislative counsel, we worked it through committees," she recalled. "I predominantly served as the expert witness. There was a lot of drama toward the end trying to negotiate it and get it on the Senate floor for a vote, and then when it passed finally, I was on the Senate floor, and that was an amazing experience after all of that."

The team drove up to Santa Fe practically every day to work on the bill, which now that it is law, is intended to level the playing field for Medicaid patients transitioning out of nursing homes and into other living situations. During the legislative session when the bill was up for consideration, Yildiz's husband's health was declining.

"It took me away from home long days," said Yildiz, "and it was a time when he was the most compromised, most ill, and even then he supported

this fully. We were married for 18 years, but he also had full understanding in terms of how important this stuff is -- (how it affected) people's lives."

Other people's lives are consistently on Yildiz's radar. She sits on the Policy Committee for the Aging and Long Term Services Department for the state of New Mexico. Her agency has taken a lead role in developing access to resources for Native American people living with disabilities. She's president of a board for a new non-profit that grew from her involvement with a subcommittee of the Affordable Housing Committee for the city of Albuquerque.

"What we're trying to do with this new non-profit is transition out of the city of Albuquerque because it has taken (on) a life of its own and then just continue and expand the work, so we're educating throughout the state about incorporating universal design into home building."

The committee that built the non-profit, known as Universal Design New Mexico, has worked closely with the Homebuilders Association.

"Since 2003 our subcommittee has been judging homes based on universal-design features we've developed and packaged and shared with anyone who wants to see it, especially home builders. We've had entries every year of model homes in the Parade of Homes -- they also give out other awards. With the universal-design award there's been an average of 10-12 homes we've judged for universal design. Of course, we've done a lot of training beforehand with people who want to enter their homes, of how to incorporate universal-design features into their homes."

Housing is but one resource Yildiz and her ILRC helps people secure.

New Mexico's large Native American population offers cultural and language barriers other ILRCs might not face. Yildiz was very excited to discuss how her center has faced the challenge.

"We really helped lead that effort," she said. "Basically, there are 19 Pueblos, two Apache tribes (Mescalero and Jicarilla), and the Navajo Nation. We started out back in 2005 because a lot of the Pueblos are in our service area, and I thought the best model to serve Pueblo PWD (persons with disabilities) in our service area would be to help them start an independent living center on the Pueblo, controlled by PWD on the Pueblos. That can't happen by Anglo people with a center headquartered in Albuquerque. So we applied for some Part C funding to start a community conversation about independent living philosophy and starting a center. We identified two emerging leaders we knew from our center to help lead this effort and put on community meetings."

The two original liaisons, Juana Valencia and Joseph Ray, are still involved in the project, now called NAIL, (Native American Independent Living), which is working on two sites. Ray, a person with a disability, is the executive director of the new center based on the Laguna Pueblo, his home; Valencia is from San Felipe Pueblo, the other NAIL site.

"We helped them incorporate as a non-profit," said Yildiz. "We started out trying to get a center by and for Pueblo people with disabilities on a reservation. I'd say we've been affiliated with, and I've been affiliated with, some amazing things here. (That) keeps me inspired."

Amy Halloran is a writer who lives in upstate New York with her sons and husband.

At 25, WID Still Making a Difference

By Janine Bertram Kemp

With gospel soul provided by the Blind Boys of Alabama, the World Institute on Disability celebrated its 25th birthday at a bash at the Oakland Marriott this past November.

WID, founded by Judy Heumann, Ed Roberts and Joan Leon, was created as a think tank for the disability rights movement, a place for policy research and training that did not stop at the U.S. borders. Twenty-five years later, the Oakland-based institute remains on the cutting edge of research and training while empowering people with disabilities.

"Initially, WID wanted to add bona fides to the disability life experience," said Kathy Martinez, executive director. "We worked in areas like personal assistance services and transportation, researching the cornerstones of independent living (IL) philosophy. While the whole country isn't ramped, there is a lot of work still occurring promoting policy and practice around the core IL areas. Many disability groups -- NCIL, AAPD, ADAPT -- have this focus. Assuming we have basic access, the next move on the chess board is economic self-sufficiency."

WID's main focus, Martinez said, is helping provide people with disabilities (PWD) obtain employment support, not entitlements. WID does research and training and disseminates a prodigious amount of information. It works with government agencies, non-profits and disability organizations to provide training and affect policy.

Martinez spoke of WID's networking with the Social Security Administration. At SSA, the basic definition of disability is that one can't work and must live at

the poverty level to keep receiving benefits. That could be a problem for anyone on disability who tries to save money or accumulate resources.

"I was a disabled child and was on SSI," Martinez said. "Part of me thought, 'Why should I work?' Living on benefits is poverty, but it's secure poverty. If it weren't for role models like Judy Heumann, I may not have made the stretch. If we change the expectations of society and get the government to provide real employment supports, economic self-sufficiency becomes viable."

To that end, WID came up with Access to Assets, an anti-poverty approach designed for women during the welfare-to-work years that includes home ownership, savings, education and microenterprise. WID is the liaison between the disability and asset-building fields.

"Financial literacy is important to people with disabilities, and there is a lot of push back against it," said Thomas Foley, program manager. "Much of our work is disseminating enough information to change expectations. Many people with disabilities think they cannot own their own home and keep benefits. You can own your house, make 53 grand a year, have half a million in an IRA and still keep your benefits."

Access to Assets provides information on programs available to help with financial empowerment. There is a program for first-time home buyers that provides \$69,000 for a down payment. California allows people to use Section 8 (a federal housing-assistance program) to pay their mortgages. Foley is aware of several instances in

which it was cheaper for people with disabilities to buy a home than rent.

One example of the depth and breadth of WID's online info is the Web site www.disabilitybenefits101.org (DB101). As part of WID's California Work Incentives Initiative, DB101 brings together rules for health coverage, benefits and employment programs that disabled people use. All relevant information is included and is described plainly. For anyone who has difficulty understanding archaic Social Security disability language, or the intricacies of Ticket to Work and Work Incentives, and how all of it relates to the loss or continuation of health and long-term-care benefits, DB101 is a seminal resource.

Health Access and Long Term Services (HALTS) is WID's program to address personal assistance services (PAS), medical issues and aging.

"Personal assistance is a huge area," said Marsha Saxton, WID senior researcher. "We are looking at providing funding for wages and benefits for workers in order to enable independence by increasing the pool of personal assistants. In addition, there are newly emerging populations using PAS, like people with psychiatric disabilities and chronic illness. WID is also looking at multicultural issues and how racism and discrimination impact PAS."

As part of long-term care, WID is addressing the issue of violence against and abuse of people with disabilities. "Studies present a range of statistics, but the rate of abuse of women with disabilities is about three times that for non-disabled women," Saxton said. "We are just finishing CAPE: Curriculum on Abuse Prevention and Empowerment. We will be publishing 'Sticks and Stones: Disabled People's Stories of Abuse, Defiance, Resilience.'"

"Sticks and Stones" will be available on the WID Web site, distributed through e-news vehicles and placed in some libraries and bookstores.

HALTS helps provide cultural training of medical professionals to improve health care. "My great love is training health care providers of all kinds about compliance with the ADA and culturally sensitive provision of care," Saxton said.

HALTS created "Access to Medical Care: Adults with Physical Disabilities," a 20-minute video that focuses on issues that affect the quality of care for patients with disabilities in outpatient clinical settings. It addresses cultural competence, access and communication issues in the clinic, common myths and stereotypes about disability that interfere with accurate assessments of patients, and barriers to health care delivery. (Independence Today readers and disability organizations can receive a free copy in VHS format by contacting Saxton at marsha@wid.org).

WID's Project Vision (Proyecto Vision) is the first national technical assistance center for Latinos with disabilities. It provides services to employers, service providers and job seekers to address barriers to Latinos effectively using disability services and connecting to work.

"We provide resources for Latinos with disabilities around employment and access to education," said Gabriel Many, project manager. "We work to make sure that Latinos with disabilities get access to the resources of the disability community."

WID stays involved on the international scene, as well. The organization

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FOR DIRECTORS ONLY

Revised IRS Form 990 Requirements

By Patricio Figueroa, Jr.

For years the Internal Revenue Services (IRS) has been exploring ways to obtain more information from the ever-increasing sector of corporations, or organizations, that is not-for-profit (or non-profit organizations, NPOs). Consequently, for nearly a decade the federal agency attempted to modify IRS Form 990. When the draft Form 990 redesign was released on June 14, 2007, the IRS requested comments, including those regarding the elimination of Form 990-EZ and the modification of its filing thresholds (or gross receipts). The Form 990 revamp did not contemplate discontinuation of filings of the Form 990-EZ for at least some time.

This new IRS Form 990 was designed to be a significant departure – in both format and substance – from the old Form 990. Rather than a “one size fits all” approach, the draft Form 990 relied on a “core” form that would be filled out by all organizations, together with a lengthy set of schedules that would be filled out depending on the particular type of organization (for example, a school or hospital) and on its particular activities (for example, whether it conducts activities outside the United States, receives non-cash gifts or engages in transactions with board members or other interested persons). The new Form 990 covers tax years beginning in 2008, which means that the earliest due date for the new Form 990 is not until May 15, 2009.

But during the review or comment period that started in April 2008, when the IRS released voluminous draft instructions, many organizations suggested retaining Form 990-EZ and increasing its filing thresholds to allow a greater number of small NPOs to use it instead of Form 990 (core form). Currently, the IRS is retaining Form 990-EZ so that small organizations may continue to file it. The form was revised to ensure that required information continues to be reported in future years.

The IRS dictates which version of Form 990 is filed by an NPO, based on annual receipts instead of the type and purpose of the organization. Once the IRS recognizes an organization as tax-exempt (public charity status), reporting requirements vary. Most religious organizations, as well as businesses whose gross receipts total less than \$25,000 per year, are not required to file annual information returns.

The majority of recognized charities fall into one of these two groups (all other organizations are required to file an annual information return): those filing IRS Form 990 (for organizations with annual receipts of more than \$100,000 or total assets more than \$250,000), and those filing IRS Form 990-EZ (for organizations with annual receipts of less than \$100,000 but at least \$25,000 and total assets less than \$250,000).

This year the revisions go into effect. The 2008 Form

990 core form incorporates significant revisions to the draft released in June 2007. Revisions to the core form were driven by two goals: 1) to ensure that the form appropriately collects information regarding the various types and sizes of exempt organizations required to complete the form, and 2) to address the concerns expressed in public comments regarding the draft's burden minimization, transparency and tax compliance objectives.

Keep in mind that the size and complexity of the various types of NPOs range from small charities to universities to the N.Y. Stock Exchange to the American Red Cross. Thus the former case was largely part of the force that drove the changes.

About one-third of the charities readily recognized by the public must file one of these two forms.

IRS Form 990 is a public document. This reminder to organizations completing the form is printed on it:

Form 990 is available for public inspection and, for some people, serves as the primary or sole source of information about a particular organization. How the public perceives an organization in such cases may be determined by the information presented on its return. Therefore, please make sure the return is complete and accurate and fully describes, in Part III, the organization's programs and accomplishments.

The above means that any member of the general public can walk into the offices of an NPO and demand to view a copy of the form. It is unclear whether these requirements also allow for a copy to be made for inquirers. The general operating policy is that no copies are required.

The current Form 990-EZ consists of basic information asked of all organizations that file the form, as well as Schedule A, Organization Exempt

under Section 501 I (3), Supplementary Information, and Schedule B, Schedule of Contributors. As set forth below, Form 990-EZ requests information regarding special events and gaming, political expenditures, excess benefit transactions, donor-advised funds, and liquidations, dissolutions, terminations or substantial contractions.

Schedule A, applicable to 501 I (3) organizations, requests information regarding compensation of independent contractors and highest compensated employees, the basis for an organization's public charity status, a private school's nondiscrimination policies and practices, lobbying (which is a taboo activity), specified activities posing compliance concerns, and transactions or relationships with non-charitable exempt organizations (mentioned in a previous column). Schedule B is filed by 501 I (3) organizations and certain other businesses to report certain charitable contributions and contributor information. In other words, the IRS wants to know how an organization's funds are being used.

In order to allow both Form 990 and Form 990-EZ filers to use the same schedules for 2008 and later years, Form 990-EZ has been modified to allow the use of new Schedules A, C, E, G, L and N from the 2008 Form 990. These schedules are used to report information currently required by Form 990-EZ. In addition, certain information no longer required to be reported on the 2008 Form 990 as a result of its redesign has also been eliminated from Form 990-EZ. For many NPOs, this will signal a new way to keep records, in relation to their activities and how much management is paid.

For board members and would-be donors, of

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course, your particular interest in the organization whose Form 990 you are reviewing will influence what information you may consider significant. For example, if you are thinking of contributing to a nonprofit, you may want to know what it does and how strong it is financially (its ability to attract resources, its level of reserves, etc.). If you are a board member, you may be interested in reviewing your own nonprofit's Form 990 for information that might prove embarrassing upon inspection by the public. Some believe that board members have a responsibility to review their organization's Form 990 before it is filed (Please consult with your accounting firm regarding requirements for your NPO.)

Having stated the information above, in February 2009, GuideStar, the leading provider of nonprofit information, reported that half a million nonprofits could find themselves stripped of tax-exempt status in May 2010. According to IRS estimates, that's how many smaller organizations have failed to file a Form 990-N. The Pension Protection Act directs the IRS to revoke the tax-exempt status of any organization that fails to file an annual return, including the 990-N, for three consecutive years. Revocations will happen automatically beginning in May 2010 (www.irs.gov/charities/article/0,,id=169250,00.html).

For more on GuideStar, go to: <http://www.guidestar.org/index.jsp>. I would strongly recommend that you check to see if your organization is in its database.

*Patricio Figueroa, Jr. is an artist, author, advocate and co-founder of **Independence Today**. He was also the first director of a center for independent living (CIL) in New York state.*



Disability Funding Included in

Stimulus Package

On February 17th, President Barack Obama signed into law the largest stimulus bill in history. Within the bill are several provisions that affect the disability community. The American Recovery and Reinvestment Act (ARRA) included funding for independent living to the tune of \$87.5 million for Part C centers for independent living and \$18.2 million for Part B state grants.

Congressman David Obey, D-Wis., chair of the House Appropriations Task Force, was the person most responsible for including independent living programs in the House stimulus package, and Senator Tom Harkin, D-Iowa, championed it in the Senate. It was the hard work of NCIL's advocates in Wisconsin that taught Congressman Obey that the independent living program is a worthwhile investment.

Senator Harkin promised NCIL advocates at its 2008 march and rally that he would double our funding, and he made sure IL funding was not removed from the stimulus package. Furthermore, when the stimulus package came under fire from fiscal conservatives and other opponents, it was NCIL's policy team and advocates around the country that wrote, called and visited with members of Congress to ensure that the funding was protected.

Now that the bill has been signed into law, NCIL is working with members of Congress and the Rehabilitation Services Administration (RSA) to ensure IL funding is

distributed according to congressional intent.

A meeting has been requested and questions have been submitted to RSA. NCIL will keep the members updated with any new information it receives. In the meanwhile, check the Department of Education's Web site for updates on how the Part B & C funds will be distributed. Part C funding data is not on the Web site now because distribution is still being decided upon. NCIL has been told a decision will be made soon.

In the following categories that relate to people with disabilities, the stimulus package will provide:

Employment

- \$540 million in vocational rehabilitation state grants.
- Funding to modernize the unemployment compensation program.
- An additional weekly unemployment insurance benefit of \$25.
- A continuation of extended benefits through December 31st, 2009.
- A temporary suspension of federal income tax on the first \$2,400 of unemployment benefits per recipient for 2009.
- \$500 million for adult and \$1.2 billion for youth job-training services.

Special Education

- \$11.3 billion for the IDEA state grant program.
- \$500 million for the IDEA Part C early intervention program.
- \$400 million for the preschool program.

Social Security

- A one-time payment of \$250 to disabled veterans and recipients of Supplemental Security Income and Social Security.
- \$500 million to help the Social Security Administration reduce processing time for claims and appeals decisions.
- \$500 million for the SSA to replace its antiquated national computer center.

Services for the Aging

- Funding to the secretary of U.S. Department of Health and Human Services to support a study of the use of innovative technologies to assist the elderly, individuals with disabilities and their caregivers throughout the aging process.

Outreach Programs

- \$90 million for education and outreach, including grants to organizations for programs to educate vulnerable populations, including senior citizens, minority communities, people with

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has completed programs in Russia, Uzbekistan, Georgia, Armenia, Vietnam and Central America that identify disability leaders and develop advocacy skills as a path to economic empowerment. Martinez stressed that WID is committed to sharing the training, providing technical assistance -- and then letting go. "These leaders are the real experts in their own countries and culture," she said. "We did a project in Russia called Perspektive. Now they are larger than WID and hire us on contracts."

WID is currently collaborating with Mercy Corps, an Oregon-based non-governmental organization, on a skill-development project in Iraq. Iraqis with disabilities, including women, are beginning to share experiences and develop skills. Bruce Curtis, program manager, took a Whirlwind chair overseas so that Iraqis with disabilities could see how it can be constructed using indigenous materials. The Whirlwind is a chair designed by Berkeley engineer and activist Ralf Hotchkiss, who has quadriplegia. It uses materials similar to those used in the making of bicycles. Curtis has arranged for 120 Whirlwinds to be shipped to Iraq.

"Disabled people face environmental obstacles and attitude obstacles, and both need to be changed," Curtis said. He doesn't claim expertise in the various tribal cultures of Iraq, but he is expert in helping develop skills in areas of advocacy and "training the trainer" programs.

In January, he will return to Iraq to train 50 people with disabilities. Last May, he trained 35 participants and tasked them with training 1,520 Iraqis, disabled and non-disabled,

schoolchildren, government officials and the general public. Four months later, he learned they had educated 6,000 people about disability.

"Everybody would like to do something to help deal with all the death and destruction the war caused in Iraq," Curtis said. "I want to make sure disabled people are in the mix of rebuilding their society."

In each WID program area, the theme of economic empowerment looms large. "If disabled people don't have the resources, we still have no power," Martinez said.

More information can be obtained online at www.wid.org. The Web site provides calculators for benefits and information on PAS, education, work, Medicare and Social Security. Information is geared for California residents but much is relevant nationwide.

Janine Bertram Kemp is a freelance writer and longtime disability rights activist. She is a member of ADAPT and serves on the board of the Disability Rights Center. Formerly of Washington, D.C., she now lives on the west slope of Mt. Hood in Oregon.

This Day
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Anatomy." He told Barbara Walters on her 2008 Oscar special that he thinks dyslexia has "given me a perspective of — you have to keep working. I have never given up." After his mother was diagnosed with ovarian cancer in 1997, the actor helped start the Patrick Dempsey Center for Cancer Hope and Healing in Lewiston.

Feb 22nd, 2005 — John Hockenberry's scathing review of the film "Million Dollar Baby" is published, garnering international attention. Hockenberry's essay, titled "And the Loser Is," was printed by a disability Web site called "Million Dollar Bigot" formed to protest

Kahrmann
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declined; others repeated briefly what they'd said. Finally, Kahrmann focused on a person who had entered with him. As this person gradually opened up to the group, it became clear that Kahrmann had been late because he was administering some personal care. This person talked about loneliness and having a hard time leaving the house. Those in the group, after hearing the whole story, tried to make the person feel less alone by offering advice based on their having faced similar issues.

"What I care about most is the right of every individual to be who they are in the world," Kahrmann said later. He said he gained this sense of humanity, in part, from his father, who always allowed him to be exactly who he was. Kahrmann felt entirely safe with his dad, who died suddenly when Kahrmann was 15. His father was 55, the age Kahrmann is rapidly approaching. He is aiming to finish his memoir the day that he outlives his father's age; he plans to remember

the 2004 film co-produced by Clint Eastwood. The essay, rejected by at least one mainstream media outlet, was quoted by Paul Krugman of *The New York Times* and was mentioned in Australian and Indian media outlets. The Web site received several hundred thousand hits the week after the film won the Oscar for "Best Picture." A documentary, highlighting opposition to the movie, also called "Million Dollar Bigot" was later filmed. It is available on Google Video.

-- **Compiled from various sources by Mike Reynolds**

Do you know of an important date in disability history? Send it to Mike Reynolds at: uppitycrip@gmail.com

the moment at his dad's grave.

Kahrmann's unfinished memoir is a wild read -- a lively account of his life, the layers of events building one upon another to create a huge and startling whole. Adopted when he was a newborn, Kahrmann danced with the Joffrey Ballet as a teen, lost his adoptive father, fell into mischief that led him to juvenile detention, and lost touch with his adoptive mother. He reunited with her before he was shot in 1984 and reunited with his birth mother after he was shot.

His resume includes more than 20 years of work in human services and jobs as a cabdriver and a freelance writer. He was on disability from 1985-1992 and has just gone on it again. While the fatigue associated with brain injury has increasingly affected him, he has done three lengthy bike rides and run a marathon. Some of the bike rides covered up to 1,000 miles, and some began from the site of his shooting. In a recent event, people joined him for small chunks of the fund-raising rides -- west to Buffalo and back to Albany -- held to increase awareness about brain injury.

"The Life Growth philosophy of identifying a goal and what is getting in your way truly helps you conceptualize not just the goal, but the obstacle as well," said Mary Myers, a member of Kahrmann's BIANYS support group. "When the impediment gets definition, it gives you something to focus on and work toward overcoming."

Myers, who described herself as overcoming an emotional trauma, said she feels completely at home in the group. She attends weekly and has established solid friendships.

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Kahrmann
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Dave Listowski lives with TBI and has known Kahrmann for more than a decade. Thanks to Peter's example and suggestion, he helped start a brain injury support group in East Syracuse that meets monthly.

"I consider it his group because he inspired it," Listowski said.

Kahrmann continues to work to develop awareness and to help people help each other and themselves through the BIANYS support group. He is also active on the New York State Independent Living Council and loves to speak publicly about brain injury and the Life Growth philosophy.

"I want to do as many speeches as I can," he said. "I like to lift people up and want to get Life Growth into as many venues as possible."

Amy Halloran, a writer, lives in upstate New York with her sons and husband.

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News Briefs

*supplied by David Reynolds
from Inclusion Daily
Express.*

www.InclusionDaily.com

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disabilities, low-income individuals and people living in rural areas. The funds can also be used to provide one-on-one assistance for installing digital-to-analog converter boxes for these populations.

Housing

- \$4 billion for building repair and modernization.
- \$250 million for a new program to fund energy retrofits of Section 811 supportive housing for persons with disabilities, Section 202 for the elderly, and project-based Section 8 units to make them more energy efficient.
- \$2.25 billion with \$2 billion targeted to fill gaps in approved low-income housing tax-credit projects for home-investment partnerships.
- \$1 billion to support community development block grant housing in hard-pressed localities.
- \$1 billion for housing, food, employment and health care to serve areas hardest hit by the recession.
- \$2 billion for communities to purchase and rehabilitate foreclosed, vacant properties to create more affordable housing.
- \$5 billion to weatherize homes

Health care

- An \$87 billion increase in the federal government's share of Medicaid spending, which runs from October 1st, 2008, to December 31st, 2010. Sixty-five percent of the funds will be given to all states. Thirty-five percent will be used for additional payments (in the form of a decrease in a state's match) for states with high unemployment rates. Each state will receive a "base" 6.2% increase. (There is a "maintenance of effort" requirement that prohibits states from changing eligibility, but there is no maintenance of effort provision for benefits or services. Therefore, it is critical for affiliates and chapters to meet with their state mental retardation and developmental disabilities and Medicaid agencies, their governor's office and state legislature immediately to urge them to use this increased funding for disability services.)
- A 65% COBRA premium subsidy for nine months.
- \$19 billion to jumpstart computerized health records.
- \$1 billion to prevent chronic diseases and to increase immunization

of low-income households to reduce energy costs.

programs.

- \$100 million in competitive grants to localities and nonprofits to remove lead paint in low-income housing.
- \$10 billion for increased National Institutes of Health biomedical research.
- The stimulus package also extends a moratorium on Medicaid regulations that are in "final" form (e.g., school-based services and transportation, targeted case management, and outpatient rules) from April 1st through June 30, 2009. The package also contains a "Sense of the Congress" that the secretary of the Department of Health and Human Services shall not publish any pending Medicaid rule (including the proposed rehabilitative services option) in final form.

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Lewis
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was no easy commitment.

The first day, our group picketed and handed out leaflets on the sidewalk in front of the AMPAS building in Beverly Hills. That was also the day those attending the awards had to pick up their tickets. Among those accepting and reading our leaflets were John Lithgow and character actor Richard Libertini.

Bearing a petition protesting Lewis' award signed by more than 2,600 people, we came to present it to Bruce Davis, the executive director of AMPAS. We were told no executives or board members were in the office.

Later, the Beverly Hills police came and tried to evict us. After they threatened to take names, Laura Hershey asked, "Are you going to arrest us?" "No one said anything about arrest," a police officer replied.

We would not move or back down.

Finally, Davis, the official we were told was not in, met with several of our leaders. He admitted being aware of the longstanding concerns of the disability community about Lewis but defended the award, pointing to the large sums of money the comedian has raised for the MDA. Davis asked the group whether those funds have not done some good.

Unanimously, we responded that the harm done to disabled people's public image far outweighed the impact of the research dollars.

"The issue is how he raised that money," author and scholar Simi Linton told Davis. "Jerry Lewis trades on our dignity."

On Saturday and Sunday, we protested near

the Kodak Theater at Hollywood and Highland while handing out thousands of leaflets. People in the crowd stopped to talk with us, and many appeared to understand that Lewis is no humanitarian and that the MDA telethon hurts the cause of independent living for people with disabilities.

The media coverage was widespread, particularly on Saturday and Sunday. Several reporters asked if we had accomplished our goals given that we did not stop the academy from presenting its award to Lewis. Most in our group would agree that we had.

Non-disabled society has a difficult time understanding the issue of dignity and societal inclusion vs. the pity-and-charity model. Conveying the independent living perspective is a long-term proposition. We called public and media attention to the issue. AMPAS, Lewis and MDA were made aware that we took a stand against the comedian being called a humanitarian at our expense.

Personally, I only saw two of our leaflets discarded on the ground, which is a record. People were actually reading them.

Moreover, we had the privilege of being in a community with one another, of working hard, laughing, reaching exhaustion together and still moving forward. Pulling off a protest like this creates a sort of band of sisters and brothers, a camaraderie that is not to be missed. Perhaps it is this magnificent joining that writer and philosopher Albert Camus referred to when he said, "The struggle is its own reward."

The journey is the destination.

Janine Bertram Kemp is a writer and disability rights activist who lives in Zig Zag, Oregon.

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said there was no place where it was acceptable for another student to read aloud to me, so we did our reading in the women's room!

The point is, I was on my own to get my books, schedule exams, introduce myself to my professors, and get by.

This was a small campus in Michigan. I had no idea then that, although I was one of 2,000 at my school, students with disabilities were beginning to make their mark on campuses around the country. Some were even organizing and influencing significant architectural and attitudinal changes.

Four years later, I attended graduate school at a large state university where, already, the climate with regard to disability constituted culture shock. There was an office specifically devoted to what were then called "handicapped students." Even more thrilling, though, knowledge of that office was followed with a kind of euphoria as I began actually meeting other students with disabilities. I met other blind students, a deaf woman, kids with manual and power wheelchairs, a guy with leg braces, another guy with cerebral palsy – and it was like coming home at last.

For the 18 months of grad school, I enjoyed the social aspect of having other students with disabilities around me, but the accommodations concept was too new for me to reap any benefit academically. In other words, I finished my education before the protection of the 1977 504 regulations to the Rehabilitation Act were passed and long before the 1990 Americans with Disabilities Act came into being.

In the 1860s, Gallaudet was formed as the first

post-secondary institution of learning committed to educating deaf students. After World War I, some colleges and universities around the country began looking at ways to include returning veterans with disabilities, and that effort was stepped up significantly following World War II. The concept of such students having rights, however, wouldn't come on the radar screen till the baby boomers with disabilities realized that all the civil rights action and legislation regarding African-Americans and women resonated exactly with the discrimination they were experiencing as well.

Offices to provide services to students with disabilities began cropping up around the country with some rapidity in the 1970s, and the numbers of students with disabilities seeking college degrees increased right along with them.

Whereas in the 1950s and '60s, scholars stated that the only students with disabilities attending college were the most highly motivated, the idea that disabled students had the same rights as nondisabled started spreading. In 1978, 2.6 percent of all incoming full-time freshmen identified themselves as having a disability. In 1994, that number had grown to 9.2 percent. And it just keeps growing.

According to Richard Allegra, president of the Association of Higher Education and Disability (AHEAD), there are currently more than 1,000 institutions holding membership in this organization, which represent only a third or maybe a fourth of the total number of offices for students with disabilities operating around the country.

In other words, while it was perfectly legal in

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1969 to make a student promise that she wouldn't ask for any special accommodations – or flatly deny admission regardless of ability – students today can pretty much count on some level of built-in special assistance when they get to campus.

Common academic accommodations include accessible classroom location; priority registration; early syllabi; assistive technology; course requirement modification; open- or closed-captioned videos; readers; interpreters; note takers; conversion of materials into audio, electronic or Braille formats; extended test times; and a number of other adjustments. All of this sounds terrific, but there are two inherent problems with the status quo that worry this baby boomer who had to schlep that bulky typewriter through the snow.

First, there are no disability services police. AHEAD suggests best practices and professional standards, but if a college is ignoring one cohort and favoring another or, worse, providing useless accommodations in some cases, there's no overseeing body to tell them to straighten up.

Second, I wonder if the sense of entitlement might be sometimes weightier than the sense of accountability for some of today's accommodated students.

For those of us who attended college before the laws were in place to protect our rights, the expectations placed on us were often one big, fat wake-up call. It was my responsibility, for instance, to get my books in recorded format. If I didn't

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Mental Illness
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nervosa (self-starvation) and bulimia (binging and purging), have potentially life-threatening fixations on food and an irrational fear of being fat. An obsession with exercise may be included.

Some common myths concerning mental illness include:

- 1) Children and young people do not have mental health problems.
- 2) People with psychiatric problems should be institutionalized.
- 3) Anyone with a mental illness can never lead a normal life.
- 4) Anyone who is mentally ill is dangerous.
- 5) Those challenged with mental illness can never work in important or responsible positions.

In fact, in this country, more than 6 million young people may suffer from a mental health disorder that severely disrupts their ability to function at home, in school or in their communities. According to HealthyPlace.com, the percentage of Americans who will suffer from a form of mental illness in their lifetimes ranges from 1.4 (agoraphobia without panic) to 16.6 (major depression disorder), and the average amount of time, in years, until those people receive treatment ranges from three to 20 years (see chart on this page).

With proper care and treatment, a person with a mental illness can recover and resume "normal activities." Treatment and care, however, take money and access. In addition to health insurance, the availability and acceptability of services, cultural appropriateness, location, hours of

Mental Health Comorbidity Data (U.S.)

	% of pop. that will be affected in their lifetime	Average years until treatment
Anxiety disorders		
Panic disorder	4.7	10
Agoraphobia (w/o panic)	1.4	12
Specific phobia	12.5	20
Social phobia	12.1	16
Generalized anxiety disorder	5.7	9
Post-traumatic stress disorder	6.8	12
Separation anxiety disorder	1.6	no data
Mood disorders		
Major depression disorder	16.6	8
Dysthymia (mild clinical depression)	2.5	7
Bipolar I-II disorders	3.9	6
Impulse disorders		
Oppositional defiant disorder	8.5	9
Conduct disorder	9.5	6
ADHD	8.1	6
Intermittent explosive disorder	5.2	5
Substance		
Alcohol abuse	13.2	9
Alcohol dependence	5.4	6
Drug abuse	7.9	6
Drug dependence	3.0	5

operation, transportation and costs must be met if a person with mental health challenges is to survive.

Access means more than having health insurance or the ability to pay for services. It also means that mental health professionals and services must be available where a person lives. Further, it means that those personnel and services are available in a culturally acceptable context. For example, many parishioners of African-American churches would not travel to a therapist's regular office but would see that professional if he or she had an office in their or another church.

A potential client without transportation to a clinic, or one who cannot afford to pay for it, does not have access to proper care and

treatment. That is also the case if that client cannot reach the clinic during its regular hours.

Based on the aforementioned statistics, anywhere from 22% to 65% of those with mental illness in any form, including children, do not have access to proper care and treatment and thus cannot recover from mental illness and resume "normal lives."

Brenda Brown-Grooms is an independent living coordinator with the Blue Ridge Independent Living Center in Roanoke, Va. She is also an ordained Baptist minister.

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contact my professors early and get my titles or the hard copies of texts to the recordings for the blind and dyslexic headquarters in time, well, I just wouldn't have books when classes began. If I didn't find, hire and schedule readers, I wouldn't know what the printed material was that we were required to read. If I didn't get a professor's permission to take the exam in a separate room, obtain a reader who could read the questions to me, and find a spot where the clackety-clack of my typewriter wouldn't disturb anyone, well, I guess I would just have failed.

If you're going to be a student with a disability, there's no better time in history than now to do it, but those of us who have marched and fought and stood on the shoulders of others who marched and fought even harder have a responsibility to educate today's students with disabilities about more than astronomy and Shakespeare. While some students I spoke with for this article are indeed responsible for getting their own accommodations in place, many are removed from the process, simply expecting staff in the disability services office to take care of academic issues. All of us can make the disability community a healthier one by imparting to students news of the legacy they have received when it comes to "rights" and the responsibility they have to themselves and others to be accountable for their own accommodations.

For those who need an alternate classroom location or a sign language interpreter or a set of class handouts converted into Braille, there is much more at stake in utilizing the resulting accommodation if you played a role in achieving it. And if you had a role in putting the accommodation you

needed into place, you're also more likely to look at the bigger picture and want to get involved with improving the equality of academic life for everyone. When the rights are aligned with responsibilities, it is truly an amazing era to be a college student – with or without a disability.

Deborah Kendrick, a newspaper columnist since 1986, is senior features editor for AccessWorld.

Having a Ball at Inauguration Weekend

By Mike Reynolds

I never thought I'd ever make it to any sort of inaugural ball. I had been offered tickets to one in 1997 after President Bill Clinton was sworn in for the second time, but I didn't make it. I was in college at the time and didn't even own a suit, let alone a tuxedo -- or know where to rent one.

So when the opportunity arose to attend the Disability Pride and Power Ball, I knew it was one event I could not miss. The ball was held at the National Press Club, right in downtown Washington, D.C.

From the first moment I rolled in, armed with my ticket to the ball and two free drink tickets, I knew this was going to be a memorable night. The narrow hallways were filled wall-to-wall with incredibly well-dressed people in a jovial mood. The fact that I recognized so many faces from the disability community and saw a bunch of folks I had never met made it feel like a historic occasion.

The Disability Pride and Power Ball was historic for a number of reasons. For one, it was the first time that the people with disability, as a political group had their own inaugural ball, where folks using assistive technology probably outnumbered



Kareem Dale, special assistant to the president for disability policy,

those who did not -- as evidenced by a dance floor populated with all sorts of crutches, canes and wheels. The biggest problem I saw was the fact that, because there were so many people there, it was impossible to find anyone easily.

At one point, Marcie Roth, CEO of ADA Watch and one of the organizers of the event, insisted I follow her. Roth's insistence paid off, as I got a great view of Geri Jewell's stand-up comedy act, along with a dance routine by performance artist Bill Shannon.

Jewell is best known for the 1980s sitcom "The Facts of Life," in which she played a student with cerebral palsy. At the ball, Jewell made it a point to discuss the "iampwd.org" campaign, a push to get actors with disabilities an equitable percentage of roles in film and on television.

Shannon, who has danced in prestigious festivals around the world, completed a residency at the Bates Dance Festival in Lewiston, Maine. He often integrates a skateboard and modified crutches into his dancing. Though I had previously seen a video of his performance, it was my first time seeing him live; he was nothing short of incredible.

The evening's emcee was none other than Tony Coelho, one of the architects of the Americans with Disabilities Act. Sen.

Tom Harkin, D-Iowa, chief author of the landmark legislation, also was at the event, though I did not see him. Christina Tchen, White House director of public liaison, addressed the crowd, as did Kareem Dale, special advisor on disability issues for President Obama, who promised to engage the disability community in policy concerns.

Because the Metro was shutting down at midnight, the majority of attendees left before 11:30 p.m. As I was leaving, I was grinning from ear to ear, thinking that I'd been at one of the best events of the weekend. Barack Obama's inauguration, scheduled a few days later in front of millions of people, turned out to be fairly noteworthy, too.

Mike Reynolds is a freelance writer and short movies producer.

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