

Disability Issues

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Fred Fay Advanced Leadership Forum Held in Boston

By John Kelly

The future of disability rights activism was the subject at the Fred Fay Advanced Leadership Forum in October, as emerging leaders from across the country learned from and strategized with



Fred Fay

movement pioneers. Named in honor of disability rights leader Fred Fay, the intensive weekend at the Park Plaza Hotel in Boston was hosted by the organization he helped found, the Boston Center for Independent Living (BCIL). As stated in the forum brochure, the "comprehensive weekend aimed at giving participants the background, training, information and expertise to return to their communities and organizations and lead successful advocacy efforts for disability rights."

The intergenerational gathering of leaders was a "momentous event," said Frank Wulle, at 20 the youngest of the 21 participants. Forum organizer Bill Henning, executive director of BCIL, reported "a terrific interplay" among the pioneers and emerging leaders, with "no-holds-barred discussions" on leadership, the ingredients of a move-

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Hopes for a Disability New Deal

By Ray Glazier

Last July many of us were disappointed that neither candidate showed up in person in Columbus, Ohio for the National Forum on Disability Issues, an event intended to showcase views of the two presidential candidates on the 18th anniversary of the ADA. Now that we have elected a new President and the dust has settled, the disability community needs to review President-elect Obama's disability platform and mobilize to ensure that campaign promises get converted into action. If we don't become squeaky wheels now, our voices could be lost in the clamor of controversy about dealing with the Wall Street meltdown and the two wars we have going in the Middle East, the two (or is it three?) 800 lb. gorillas awaiting President Obama in the Oval Office.



President-elect Obama

Amidst all the statements of good intentions that both political parties put out, candidate Obama made a set of commitments in his *Plan to Empower Americans with Disabilities*. Converting campaign rhetoric into action will not happen in this economy without some painful budget decisions. So, please review the ten Democratic disability platform components outlined below, choose your issue, and make your views known to the new administration, as well as to Senators Kennedy and Kerry and to your Congressman.

Supporting Universal Screening: Following the recommendation of the American College of Medical Genetics, states will be required to provide universal screening of infants for 29 disorders.

Supporting the Genetic Information Nondiscrimination Act: Prohibits discrimination on the basis of genetic information by employers and health insurers. (Insurance industry will probably fight this, as might business associations.)

Guaranteeing Health Care Coverage: People with disabilities who lose their Medicare or Medicaid eligibility by taking a job but still cannot afford coverage will be provided a subsidy in order to purchase coverage. Moreover, under the

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MI-CEO Grant Vets

Employment Priorities at Public Forums

By Susan Murray

Generally, people with disabilities have lower rates of employment than those without disabilities. For example, the Massachusetts employment rate for people with disabilities in 2007 was 37% (with 22% working full-time) compared to a rate of 82% (with 57% working full-time) for people without disabilities. Also, among full-time workers ages 21-64, Massachusetts citizens with disabilities have lower earnings than those without disabilities, with median earnings of \$35,000 compared to \$45,000, respectively (reference – 2006 ACS).

In an effort to change those statistics and promote employment for people with disabilities, the Centers for Medicare and Medicaid Services awarded the Massachusetts Medicaid Infrastructure and Comprehensive Employment Opportunities Grant (MI-CEO) to the University of Massachusetts in partnership with the Massachusetts Executive Office of Health and Human Services (EOHHS). The grant works with a broad range of stakeholders, such as state agencies, people with disabilities, employers, policy makers, and advocacy groups, to build an infrastructure that will increase employment options for people with disabilities.

In the past year, grant staff along with its public and private partners has worked to develop a strategic plan for employment of people with disabilities in Massachusetts. In a series of public forums this fall, the MI-CEO unveiled the top priorities and strategies that will be its focus. These priorities align with Governor Patrick's priority of enhancing the economic well being of the state's citizens through job creation, as well as with the employment goals for EOHHS state agencies.

Over the next three years the grant will focus on the following priorities and goals:

Priority 1: Communicating a Pro-Employment Message to all Stakeholders • Massachusetts will undertake a broad-based communication campaign to promote awareness of employment as an option for people with disabilities.

Priority 2: Empowering People with Disabilities to Fully Participate in Employment • People with disabilities will have a voice in the development and evaluation of employment policies and programs.

Priority 3: Effectively Engaging Businesses and Employers • EOHHS agencies serving people with disabilities will adopt policies and practices that support effective business partnerships, promoting the hiring and retaining people with disabilities in the Commonwealth.

Priority 4: Enhancing Employment Services Delivery System • Individual EOHHS disability serving agencies will ensure that their policies promote the delivery of effective, person-centered services aimed at supporting participation in competitive employment for youth and adults with disabilities, consistent with EOHHS-wide employment policies.

Priority 5: Ensuring Access to Work Incentives and Benefits Information • Youth and adults with disabilities across the state will have access to complete, accurate and timely work incentives and benefits information in order to make fully informed decisions about work and earnings.

Priority 6: Strengthening the CommonHealth Working Program and other MassHealth Services that Promote Employment • The MassHealth CommonHealth Working Program will continue to function as a key employment support for people with disabilities in the state. Other MassHealth policies, procedures and services will support employment for people with disabilities.

Priority 7: Increasing Transportation Options • People with disabilities will have greater access to transportation options when going to work.

Priority 8: Tracking Employment Outcomes • EOHHS and individual disability serving agencies will effectively track employment outcome data for people with disabilities and will use it to support and enhance the delivery of evidence-based employment services.

These goals are aggressive, especially in these difficult times. Despite the recent economic challenges, Massachusetts continues to be a state with a strong commitment to serving people with disabilities. Grant staff is optimistic that, by laying the groundwork for changes to the employment infrastructure, Massachusetts will be poised to increase employment options for people with disabilities, once the economic outlook improves.

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From the Editor



"It was the best of times. It was the worst of times," wrote Charles Dickens in *A Tale of Two Cities*. And similar words could be written about the present moment.

We have a new President and a new administration. With them go exciting hopes for changes in our country's domestic agenda and foreign policy that reflect a commitment to democratic values of social justice at home and respect for law abroad. On the other hand, we are mired in an economic recession that has not only brought hardship to millions of Americans, but has had worldwide repercussions.

In this edition of *Disability Issues* we explore both aspects of the current scene. In "Hopes for a Disability New Deal" Ray Glazier details President Obama's Plan to Empower Americans with Disabilities. And in "A Bad Economy and Tough Budget Cuts Necessitate Speaking Out" Bill Henning goes over the sobering impact that the financial crisis is having on people with disabilities.

What these two articles have in common is that they both urge on us the importance of getting politically involved. This is necessary both to hold the President responsible for the promises he made during the campaign, and to protect the benefits and services we rely on from being devastated in the name of cost cutting.

I could not agree more with the advice of these two experienced advocates. Let us extend our sincere congratulations to our new, young leader and our hope that he and the disability community can work productively together.

Paul Kahn

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Obama-Biden platform, insurers will not be able to deny coverage on the basis of pre-existing conditions. (Again the insurance industry and businesses associations will be potential objectors to this.)

Improving Mental Health Care: Mental health parity was included in the Bailout Bill. But expanded coverage for veterans is new here: "...Improve mental health care at every stage of military service—recruitment, deployment, and reentry into civilian life."

Supporting the Community Choice Act and Direct Care Workers: Expand community living options vs. nursing home care with more in-home personal care services per the Community Choice Act. Address shortage of direct care workers with better wages and overtime pay per the Fair Home Health Care Act. (Both bills could be favorably treated by the Democratically controlled Congress and possibly receive union support, but face opposition from the nursing home industry, which would lose both patients and workers, and possibly from state governors eyeing their Medicaid budgets.)

Supporting the CLASS Act: The Community Living Assistance Services and Supports Act would create a new "voluntary, budget-neutral national insurance program to help adults who have or develop functional disabilities to remain independent and in their communities." Under this scheme, employees could purchase disability insurance that would provide a disability benefit that is essentially an Independence Account to purchase housing modifications, assistive technologies, personal assistance services, transportation, or other supports needed for community living. (The business community may well oppose this new benefit offering, with service worker unions possibly objecting to the expanded consumer discretion to hire family members or neighbors,

or to purchase labor-saving equipment.)

Amending the Medicare "Homebound" Rule: Changing the homebound requirement for Medicare services, in addition to freeing many people from home confinement, has major implications for home health agencies and for durable medical equipment providers who, to date, could not provide any equipment that might be used outside the home. (The bad news could be the fiscal impact on the under-funded Medicare program, especially as millions of Baby Boomers retire, become Medicare-eligible, and no longer contribute to program funding.)

Investing in Assistive Technologies: Support the Fostering Independence Through Technology Act, "which offers 21st century solutions, such as home monitoring and communications..." (This could be a boon to inventors and manufacturers, as well as to many of us, but expect opposition from the public and private insurance sectors who would pay for the new devices.)

Supporting Americans Living with Autism Spectrum Disorders (ASD): Would expand federal funding for lifelong services for people with ASD, authorizing approximately \$350 million in new federal funding for key programs related to lifelong treatments, interventions, and services for one million children and adults with ASD. More than \$1 billion in federal funding to be allocated for ASD research on the root causes and treatments. Create the ASD Program — a systems development initiative designed to promote the implementation of evidence-based practices. (The new lifetime costs of these services could heavily burden State Medicaid programs, which already constitute the largest single line item in states' budgets, as well as Federal coffers that reimburse 50 percent or more of these costs to the states. So, the insurance industry and state governors will probably be joined in their opposition by some federal officials.)

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Links to Related Information

Read the entire
"Plan to Empower Americans with Disabilities"
www.barackobama.com/pdf/DisabilityPlanFactSheet.pdf

The Kaiser Family Foundation set up a website to compare the candidates' overall positions on healthcare reform: www.health08.org/

Health08.org also has a set of video clips, in which the candidates presented their different approaches to Healthcare Reform: www.kaisernetwork.org/health_cast/health2008hc.cfm?&hc=2974

A Healthcare Access brief from the Disability Rights Education and Defense Fund lays out the issues that too many of us are all too familiar with:
www.dredf.org/healthcare/Access_Brief.pdf

Bailout Provides More Mental Health Coverage

More than one-third of all Americans will soon receive better insurance coverage for mental health treatments because of a new law that, for the first time, requires equal coverage of mental and physical illnesses. The requirement, included in the economic bailout bill enacted in October has been described as a milestone in the quest for civil rights, an effort to end insurance discrimination and to reduce the stigma of mental illness.

Most employers and group health plans currently provide less coverage for mental health care than for the treatment of physical conditions like cancer, heart disease or broken bones. They will need to adjust their benefits to comply with the new law, which requires equivalence, or parity, in the coverage. The Congressional Budget Office estimates that the new requirement will increase premiums by an average of about two-tenths of 1 percent. Businesses with 50 or fewer employees are exempt.

By wiping away such restrictions, doctors said, the new law will make it easier for people to obtain treatment for a wide range of conditions, including depression, autism, schizophrenia, eating disorders, alcohol and drug abuse. Federal officials said the law would improve coverage for 113 million people, including 82 million in employer-sponsored plans that are not subject to state regulation. The effective date for most health plans will be January 1, 2010.

Source: New York Times

President Bush Signs ADA Amendments Act

In late September President Bush signed into law the ADA Amendments Act of 2008. The purpose of the new law is to reverse the effects of judicial decisions that have excluded and left vulnerable individuals who should have been covered under the current ADA law. The courts' interpretations have over time excluded from protection many people whose disabilities can be controlled or who only experience their effects occasionally.

In a nutshell, the ADA Amendments Act strikes a balance between protections for individuals with disabilities and the obligations and requirements of employers. The law specifically overturns Supreme Court decisions that have caused many people with disabilities whom Congress intended the ADA to cover to lose important protection. It makes clear that Congress intended the ADA's coverage to be broad and to cover anyone who faces unfair discrimination because of a disability. The law clarifies the current requirement that an

impairment must substantially limit a major life activity in order to be considered a disability. It prohibits consideration of mitigating measures in the determination of whether an individual has a disability, with the exception of ordinary eyeglasses and contact lenses. And, while it affords broad coverage for individuals "regarded as" having a disability under the ADA, it also includes a provision to make clear that accommodations need not be made to someone who is disabled solely because he or she is "regarded as" having a disability.

Social Security Announces Benefit Increase for 2009

The Social Security Administration has increased the Monthly Social Security and Supplemental Security Income benefits that more than 55 million Americans receive by 5.8 percent in 2009. This is the largest increase since 1982.

Social Security and Supplemental Security Income benefits increase automatically each year based on the rise in the Bureau of Labor Statistics' Consumer Price Index for Urban Wage Earners and Clerical Workers (CPI-W), from the third quarter of the prior year to the corresponding period of the current year. Some other changes that take effect in January of each year are based on the increase in average wages. Based on that increase, the maximum amount of earnings subject to the Social Security tax (taxable maximum) will increase to \$106,800 from \$102,000. Of the estimated 164 million workers who will pay Social Security taxes in 2009, about 11 million will pay higher taxes as a result of the increase in the taxable maximum.

Source: Social Security Administration

Office of Congressional Accessibility Services Established

In September, the Capitol Visitor Center Act of 2008 (H.R. 5159) passed the Senate by unanimous consent and established an Office of Congressional Accessibility Services (OCAS). OCAS is charged with providing and coordinating accessibility services for people with disabilities and providing information and training to staff regarding accessibility. Directed by a Congressional Accessibility Services Board, composed of the Sergeant at Arms and Doorkeeper of the Senate, the Secretary of the Senate, the Sergeant at Arms of the House of Representatives, the Clerk of the House of Representatives and the Architect of the Capitol, the law is intended to result in greater accessibility to Congress and its activities.

Source: JFA

ment, new ways to organize, and next steps. Points of agreement were reached on a number of issues.

The group came to “a pretty strong consensus that there is a disability rights movement,” said Andy Imperato, president and CEO of the Washington DC-based American Association of People with Disabilities (AAPD), “but that we are not working together across all our organizational differences.” There was also agreement that “we cannot just talk to ourselves,” Imperato added. He reported that while some participants favored concentrating on outreach to groups that are progressive, others called for a broader approach. “We really want to engage the broader society, give them an opportunity to get involved, including nondisabled people.”

The importance of welcoming nondisabled people into the movement was a major point of consensus at the forum. (The role of nondisabled people has long been controversial in what started as an identity-based civil rights struggle, as evidenced by the discord in the communities served by the Northeast Independent Living Program after the appointment of a nondisabled executive director to succeed founder and present Massachusetts Rehabilitation Commissioner Charlie Carr.) Nondisabled people who have the “interest, passion, and knowledge” have an important role to play in the movement, said BCIL Youth Transition Specialist Stacy Rogers. “Whether someone has a disability or not,” commented Andy Imperato, “whether someone is inside or outside [of government and mainstream agencies], if they ‘get’ disability empowerment, self-determination, if they ‘get’ independent living philosophy — sometimes ways of dividing people are unnecessarily blunt.” Bill Henning’s opinion was that the “vanguard of the movement” should remain people with disabilities, but that the tendency towards insularity must be overcome.

The organizing mission of the forum, developing a vanguard of new leadership with disabilities, has been an ongoing topic of interest within the disability community (as covered

in the Spring and Summer 2008 issues of *Disability Issues*). Not as many young people have been active in the movement, Frank Wulle said. “Due to the post-ADA society” young people with disabilities have been mainstreamed and may not even see themselves as people with disabilities, he explained. There is also still the problem of the “shame that is unintentionally forced on people with disabilities” by the greater society. Andy Imperato described the situation as an “opportunity for us to be more strategic and proactive” and pointed to AAPD’s record of working with emerging leaders and its summer internship program. He said that the shortage of young leadership in the Boston area is not typical of the country as a whole.

The group sent a summary position letter to 16 national disability rights organizations and asked what they are doing to develop a new cadre of leaders. Participants have continued working together after the forum by conference call and e-mail. Short-term plans include organizing actions to celebrate Inauguration Day, establishing a website for continued dialogue, developing a “Disability Transition Team” for the new administration’s first 100 days, discussing a new advocacy model, and planning for another leadership forum. New ways of communicating are also in the works, such as the expansion of AAPD’s “Justice for All” electronic newsletter from its present 5000 subscription base to 60,000.

Bill Henning of BCIL described access at the Park Plaza Hotel as excellent, but participants universally hated the area’s decorative brick sidewalks. He also recounted a surprising anecdote in which one participant told him that “you have the nicest group of people in this city that I’ve ever seen, and the drivers are so much more relaxed than where I’ve been.” Now that must be some tough leader!

John Kelly is a longtime disability rights advocate and the founder of the Neighborhood Access Group.

Strengthening VA Specialty Care: With input from advocates, strengthen specialty care within the VA, including additional polytrauma centers as well as centers of excellence for Traumatic Brain Injury (TBI), PTSD, vision impairment, prosthetics, spinal cord injury, aging, women’s health, and other specialized rehabilitative care. (The VA already needs help in providing TBI and PTSD care in particular, because they are the signature health problems of so many returning Iraq and Afghanistan war veterans. And that care costs big bucks.)

Select your issue(s) and begin advocating now. Talk is cheap, but programs and services carry price tags, in efforts as well as dollars. Let’s turn hope into reality.

Raymond E. Glazier, Ph.D., is a consultant to the MA Medicaid Infrastructure & Comprehensive Employment Opportunities grant and Director of the Abt Associates Center for the Advancement of Rehabilitation & Disability Services in Cambridge, MA. He can be reached at: ray_glazier@abtassoc.com.



A Bad Economy and Tough Budget Cuts Necessitate Speaking Out

By Bill Henning

The American economy is bad. Almost daily we read about a financial institution or manufacturer tanking, unemployment numbers rising, and consumer spending sinking. Tax revenues consequently dive, and inevitably this means governments have to make budget cuts. This scenario is playing out in Massachusetts right now.

In October 2008, Governor Deval Patrick used his executive authority to make cuts totaling nearly \$1 billion to state programs as a means to address a budget deficit that may approach \$2 billion. Disability services were not spared from the chopping block, though they had plenty of company. A peek at some budget cuts reveals that there will be both immediate and delayed impact on people with disabilities.

One huge hit was to programs run by the Department of Mental Health. According to Vicker DiGravio of the Mental Health and Substance Abuse Corporation, 2,600 adults with severe mental illness will lose day services that they rely on for community support, stability, and recovery — critical elements in helping people to remain in their own homes and out of hospitals and emergency rooms. Reva Stein of the Massachusetts Clubhouse Coalition also reports that \$1 million in funding has been cut from clubhouses that serve over 8,000 people statewide with mental illness.

2,000 home care slots for elders—people needing assistance with basic daily living tasks—also are being eliminated. According to Al Norman, executive director of Mass Home Care, “These cuts are impinging on the right of elders to be cared for in the least restrictive setting.”

Another cut is the \$15 million that was slated to help the state implement its landmark Community First initiative in the spring. This initiative is designed to support an extensive service package and aggressive interventions to help people leave or not enter nursing homes.

Medicaid cuts are often the biggest dread of people with disabilities. Many were relieved when they didn't see hits on the PCA program, as occurred in 2003, the last time the state faced a dire budget picture. But Boston Medical Center and the Cambridge Health Alliance, so-called safety-net hospitals, are facing a loss of up to \$300 million in Medicaid monies. These hospitals serve many low-income people in Greater Boston, and the loss of extensive Medicaid revenues could result in closure of clinics, loss of psych beds, and a general decline of care—situations that absolutely would hurt people with disabilities.

And as bad as this all sounds, the economic meltdown isn't showing signs of easing. Michael Widmer of the Massachusetts Taxpayers Foundation told the Massachusetts Coalition of Human Service Providers that “What we have seen is chapter one of many chapters to come.” Even funding not provided by the state to key services is evaporating. Interest on trust accounts that support legal services in the state has radically decreased. Thousands may not get legal aid in the coming year as agencies such as Greater Boston Legal Services, which assists clients with housing, benefits, and healthcare issues, will have to lay off significant numbers of staff.

The big question then is: what can people with disabilities do? One essential answer is to contact your legislator and the governor to express concerns and help impact priorities on what services must absolutely not be cut in the future. Do you want to lose vocational rehabilitation services or see independent living centers cut or have your housing subsidy taken away? It's fair to say the Patrick administration has a thankless job. But it's also true that many special interests are able to pay lobbyists who work the case for their concerns at the State House. People with disabilities often don't get to work behind the scenes, so it's vital that consumers make their case themselves—now, more than ever, is the time to speak out!

It also may be true that there is opportunity in crisis. Government is not going to be adding programs and services that cost big money, so this may be the time to exert pressure for changes that don't eat up a lot of dollars but that can still advance the disability rights cause. Youth activists with Easter Seals and the Boston Center for Independent Living are proposing legislation that would establish a disability history month and disability curricula in public schools. And the Statewide Personal Assistance Coalition is looking to promote changes to protect consumer control in the PCA program.

An economic recession is here, which always is another way of saying, speak out, organize, and agitate to protect disability rights!

Bill Henning is the Executive Director of the Boston Center for Independent Living. For more information contact Bill at BCIL at 617-338-6665, bhenning@bostoncil.org.

Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs Information Briefs

AAPD Compiling Talent Bank for Next Administration

President-Elect Obama will be tasked with appointing more than 3,000 people to staff his administration. The American Association of People with Disabilities (AAPD) is committed to helping ensure that the next Administration includes qualified people with disabilities at all levels. To that end, AAPD is seeking resumes of experienced individuals who are interested in public service and have a demonstrated commitment to disability rights for inclusion in a resume talent bank of candidates for the appointment process. If you are interested in public service, forward your resume to JFA@aapd.com. AAPD will continue to accept resumes for the resume talent bank until at least March 31, 2009.

Source: AAPD

Benefits Planning Grant Transferred to Center for Health Policy and Research at UMass Medical School

Effective December 1st the SSA Work Incentive Planning and Assistance (WIPA) grant BenePLAN, previously held by the Resource Partnership, has been transferred to the Center for Health Policy and Research at the University of Massachusetts Medical School. BenePLAN staff will continue to serve beneficiaries in Berkshire, Franklin, Hampden, Hampshire, Middlesex, and Worcester counties. Essex and Norfolk counties previously served by the BenePLAN will now be served by Massachusetts Rehabilitation Commission's Project IMPACT.

The toll free number for the BenePLAN is 877-937-9675.



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