

Disability Issues

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Summer 2008

EEOC Commissioner Addresses *Employment Now Coalition*

By Susan Murray

The Employment Now Coalition met at the Volpe Transportation Building on April 18. The topic of the meeting was "State Government as Model Employer," a goal that the Coalition along with support from the Executive Office of Health and Human Services hopes to achieve in Massachusetts. Christine Griffin, former Director of the Disability Law Center in Massachusetts and current Commissioner of the U.S. Equal Employment Opportunity Commission (EEOC) was the guest speaker.

Chris began her remarks by pointing out that "employment is more than just about net worth, it is also about self worth." She said that the general public's attitudes about the capabilities of people with disabilities will not change "until we are working side by side and they get to know us." Her remarks focused on what is happening at the federal level to make the government a model employer, what works and what does not work.

Highlights of successful strategies used by the federal government include such things as appointment of an agency

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Summer Recreation Options for Families of Children with Disabilities

By Meryl Perlson

Summertime and the living is easy. Sort of. When school lets out many families send their kids off to summer camp or pack up the minivan and head for the hills. For families of children with disabilities these activities may require a little extra planning.

Summer camps and recreation programs are available for kids with special needs, but research is often required to locate appropriate ones and wait lists are not uncommon. One place to start a camp search is **The Federation of Children with Special Needs**, which publishes an annual *Summer Fun Directory* (www.fcsn.org). Previously free, the directory now costs \$5-\$10 (depending on delivery method) and provides information on over 100 summer camps and programs. Another helpful resource is **Easter Seals**, which runs its own network of day and overnight camps throughout New England (ma.easterseals.com). **Massachusetts Family Ties** (massfamilyties.org) offers information about recreation opportunities as part of its free Resource Directory.

Information about summer programs can also be found via groups that serve kids with specific disabilities. For example, local chapters of the **Association of Retarded Citizens** (thearc.org) often maintain lists of programs in their areas.

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Photo courtesy of Northeast Passage

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Some organizations, like the **Carroll Center for the Blind**, sponsor recreation programs. Activity centers, such as **YMCA**s and **Boys & Girls Clubs**, may also offer summer recreation for kids with disabilities, including Special Olympics classes and Challenger Division Little League. Costs for camps and recreation programs vary widely, but many offer scholarships and other support to insure families can participate regardless of income.

Massachusetts offers a bounty of outdoor activities in the summer, from beaches to biking to boating. Many families of kids with special needs make creative use of standard recreation equipment or choose from the growing range of adaptive sports equipment to make their favorite amusements fully accessible. For example, wearable child locator devices designed for the mainstream parent market have been used successfully by parents of kids with autism and other cognitive disabilities



Photo courtesy of Northeast Passage

to insure that they don't wander at beaches or other outdoor locations. For biking with kids who can't ride independently, some families turn to widely available bike trailers and trail-a-bikes, while others find appropriate adaptive bikes through sites like www.bike-on.com.

If you'd like to try out activities or equipment before striking out on your own, there are several organizations in and around Massachusetts devoted to connecting people of all abilities with the great outdoors. The Massachusetts Department of Conservation and Recreation's Universal Access Program (UAP) is a great starting point (www.mass.gov/dcr). The UAP offers information about accessible DCR facilities, runs accessible recreation programs (boating, cycling, hiking and more) and provides adaptive equipment at parks and beaches across the state. Each summer they publish a brochure detailing the offerings at all DCR locations.

Several programs contract with the UAP to run recreation programs in Massachusetts. **All Out Adventures** (



Photo: Northeast Passage

outadventures.org) offers low or no cost programs, along with adaptive equipment, for activities including letterboxing/geo-caching, kayaking, canoeing and cycling. Also associated with UAP is **Community Boating**, which provides accessible sailing lessons throughout the



Photo courtesy of Easter Seals

summer near Boston. Programs usually welcome people of all abilities, enabling families to participate together.

There are also independent non-profit organizations that offer outdoor recreation opportunities to people with disabilities. **Outdoor Explorations** (www.outdoorexplorations.org) programs single day and overnight trips for people of all abilities age eight and up. Costs vary by trip, but PCAs are included for free. **Northeast Passage** (www.nepassage.org), affiliated with the University of New Hampshire's College of Health and Human Services, and **Disabled Sports USA** (www.dsusa.org), run an adaptive equipment rental program that offers daily, weekly, and bi-weekly rentals of adaptive cycles, beach wheelchairs, trailriders, water skis, portable ramps, and more. Costs are roughly \$55/week. In addition, they run outdoor recreation programs that have hosted people of all ages.



Finally, what summer is complete without at least one trip to an amusement park? **Six Flags New England** offers Handicap and MVP passes for families of

kids with special needs. Available through its Guest Relations kiosk near the main gate, the passes let users enter rides via exit ramps to avoid long lines that may be prohibitive for some kids. The Handicap pass covers up to four people and specifies the maximum amount of time they will have to wait to get on a ride. The MVP pass can accommodate a larger group (within reason), and guarantees the shortest wait time possible. Guest Relations also offers a pamphlet listing accessible rides, handicap attractions, and height requirements for each ride.

While this list of summer recreation options is far from comprehensive, hopefully it provides your family with a few resources to enjoy your favorite outdoor pastimes and make your summer living a little easier.

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From the Editor

In this issue we continue our focus on leadership development among youth and young adults with disabilities. We hear from Beth Kolbe, a former congressional intern, who expresses a great sense of enthusiasm and commitment about contributing to the betterment of our lives. Talking to her, I felt a sense of hope and optimism about the future of the disability rights movement. On the other hand, I was troubled by Kevin Wreghitt's report on the ways he feels excluded from the movement by the older leaders who should be nurturing him.

Kevin chose not to disclose his own disability in his article, and I certainly don't want to violate my young friend's privacy. But I will say that I suspect one of the reasons he has felt dismissed is that there is a hierarchy in the world of disability. At the top are the people who most resemble the able-bodied in appearance, self-expression and capabilities. High achieving, athletic paraplegics are an example of this type. At the bottom are those whose bodies are shaped differently, who have behaviors associated with incompetence, such as lack of motor control and drooling, who have communication barriers, or who have cognitive disabilities. People with Down's syndrome and cerebral palsy are examples of this group.

This hierarchy represents the remains of our internalized oppression. We still want to be like the people who have looked down on us and excluded us. We still accept their values, their focus on appearance and ability as a measure of a person's worth. We still practice on ourselves the discrimination that we have learned from them.

I submit that this attitude has to change in order for us to complete our liberation. We have to learn to like ourselves for who we are, with all our differences from some mythical norm. We have to dismantle this hierarchy and democratically include every one of us in our community, nurturing and valuing the contributions that each of us can make.

This kind of self-transformation is surely as difficult — maybe more difficult — than getting rid of architectural barriers. But until we do, we will only be building a shoddy imitation of our present world that is so sadly lacking in justice and humanity. Until we do, we will not really be free.

Paul Kahn

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Interview

Beth Kolbe, Former Mitsubishi Foundation-AAPD Congressional Intern

Interviewed by Paul Kahn



Beth Kolbe

KAHN: Can you tell me a little bit about your background?

KOLBE: I grew up in Ohio; I was there for twenty years in a middle of nowhere town surrounded by fields of corn. When I was fourteen I was in a car accident. I have a spinal cord injury, so I'm quadriplegic. I use a manual wheelchair to get around.

My accident happened the week before summer when I was in eighth grade. I was the first person in my high school with a disability, but they were really accommodating. They were great. And then I applied to Harvard. I'm the youngest of three: I have an older brother and sister. Both of them stayed in Ohio for college, but I couldn't pass up the opportunity, when I was accepted. I had come to the east coast before when I was in junior nationals for wheelchair sports.

KAHN: What kind of sports do you do?

KOLBE: I'm mostly a swimmer; I swim on the Harvard team, which is such a fun and amazing experience. I didn't swim before my injury; swimming was part of my rehab.

KAHN: What year are you in?

KOLBE: I'm a senior. I just finished applying to graduate school.

KAHN: What are you studying?

KOLBE: Health Care Policy. I don't know what I want to do with it. I started by concentrating in English, then I switched to Biology, and then I fell in love with Health Care Policy, the opportunity to help people.

KAHN: And what are you applying to graduate schools for?

KOLBE: Well, I applied to law school, then also to the Harvard Health Care Policy Doctorate program. I was just accepted into the Harvard program last weekend.

KAHN: Congratulations.

KOLBE: Thank you, but what I really want to do is this great program Harvard has where you combine law school and a PhD; you earn both degrees in five years. That's my first choice. I'm still waiting to hear about law school. I spent my summer in DC where I fell in love with politics. I fell in love with the excitement on the Hill and the chance to make

policy that makes a difference.

KAHN: Tell me a little bit about your internship. Who was it sponsored by, and what did you do?

KOLBE: It was sponsored by the American Association of People with Disabilities and Mitsubishi Electric of America Foundation. I was one of six congressional interns over the summer. You have to apply to different congressional offices. I was accepted into Senator John Kerry's office first, so I jumped on that. I was so excited, because I respect him. I got to work in his office mostly doing health policy work, then constituent work. It was such an exciting experience. Probably the experience I was most excited about was this: I got to go on the senate floor with him. They don't let interns on the senate floor, but we were able to get special permission. And I was able to help with his speech a little bit.

KAHN: How do you think your internship contributed to your personal and professional growth?

KOLBE: Professionally it made me much more interested in politics. It was an eye opener that there are so many details: there are so many different policy areas that have to be taken care of. I don't think I want to run for public office, but I certainly wouldn't mind being a policy staffer. After the internship, there was an opening in Senator Kerry's Boston office to work specifically on disability issues with one of his staffers. They invited me to do that. So, throughout my entire school year I worked in his Boston office. It's completely different, because it's much more focused on his constituents; major policy issues get done in DC. But I really loved that, because you get to talk to people on an individual basis.

KAHN: Did you make important contacts during your internship?

KOLBE: Oh, definitely. I still keep in touch with my boss from the Boston office, and I'm still close with the office manager in DC. They are good contacts for the future and great people. They love their work, and they do it well.

KAHN: Were there other ways that your internship helped you or contributed to your ability to be an advocate for disability rights?

KOLBE: We congressional interns and the IT interns lived with each other. We were all college students who have an interest in pursuing disability issues. Bouncing ideas off the

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Easter Seals Provides Work and Leadership Experience for Teens

By Joe Bellil

Teens and young adults with disabilities are getting guidance from Easter Seals as they face the daunting task of finding work or furthering their education after high school.

According to the National Council on Disability, only 38 percent of working-age people with disabilities have jobs, compared with 78 percent of people without disabilities. Many adults with disabilities would like to work but are unable to find jobs, because they have no work history as teenagers. One way to close the employment gap is to provide disabled teens and young adults with the employment experience and skills they will need to find good jobs as adults and succeed in the workplace.

Easter Seals is working in partnership with the Boston Public Schools to provide vocational assessments, job training, placement and support services for students with disabilities. Funded by a federal **Project with Industry** grant, the WorkBoston Collaborative provides high school students with employment skills that will equip them to find jobs or further their educations after graduation. Easter Seals employment specialists work with each student to determine his or her interests and abilities and coach each one in how to handle job interviews, write a resume and more. Job placement incorporates a range of services, including job searches, job shadowing, internships and job coaching.

In the three years the program has been operating, Easter Seals has worked with nearly 80 Boston students and placed them in jobs with a wide range of companies where they work alongside their nondisabled peers. Students have been placed at the Harvard Club, Au Bon Pain, the Boys and Girls Club, Filene's Basement and Gaines Electric, to name a few. For many students, the positive effects of the program extend beyond the job skills they learn. In addition to making his future brighter, Rasheed Hall's weekend job at Kelly's Roast Beef keeps him off the streets and away from negative influences in his neighborhood. He likes his job, has opened a new bank account, and he's developing skills that will serve him well as an adult.

The Boston Public Schools partnership is only one way that Easter Seals is helping youth with disabilities prepare for their futures. Every summer, Easter Seals hires teens with disabilities and pays them a stipend to work in its program at

Agassiz Village summer camp in Maine. This summer 34 Easter Seals teen leaders will be working there. In addition, 30 percent of the camp staff are former teen leaders, according to Colleen Flanagan, Easter Seals camp manager. Colleen is an example of the success of this program. She is a former camper who went on to become a teen leader and then a counselor. Now she runs the entire Easter Seals camping program.

Teen leaders spend five hours a day working with campers both with and without disabilities and helping with the day-to-day activities of camp life. Their duties include assisting campers, leading activities, supporting the kitchen and office staff and serving as support staff at the waterfront. These responsibilities give them opportunities to better understand their strengths and weaknesses, and develop their confidence, self-reliance and leadership skills.

The teen leaders go through a training program before the start of camp and take part in daily training during the camp sessions. Many of the teen leaders also are involved in the **Easter Seals Youth Leadership Program**, which develops their leadership and employment skills through service learning projects. They also work in internships at Easter Seals in public affairs, development and other areas. As they grow into their leadership roles, they serve as fine role models for young people with and without disabilities.

Joe Bellil is vice president of public affairs for Easter Seals Massachusetts. For more information about Easter Seals, go to www.EasterSealsMa.org or call 800-244-2756.



Rasheed Hall (right) receiving the Easter Seals Employment Ambassador Award from Kirk Joslin, Easter Seals president

others and learning from them was a really wonderful experience. I'm great friends with all of them. And we were able to meet a lot of leaders in the disability community, a lot of people who were very influential with the ADA. My generation has grown up since the ADA. So, it's easy to take it for granted, because we didn't have to fight for ourselves. Learning from the people who did have to fight and listening to their stories was empowering. I would like to work in DC for a few months before starting graduate school.

KAHN: What are your career plans?

KOLBE: I definitely want to work in the disability field in some aspect, whether through health care policy or disability law. I can see myself working in politics, being a lawyer, or working in an academic setting doing health policy work.

KAHN: How would you rate the importance of internships for young people like yourself?

KOLBE: I think it's important to have real world experience through an internship, and the connections you make and the understanding you gain are important. At Harvard there isn't a large disability community, so I valued having an internship experience with other people with disabilities who are motivated leaders in their own right, knowing that there are other people working for disability issues. I would definitely recommend to other youth that they pursue an internship opportunity if it comes along.

Information Briefs

President Signs Genetic Information Nondiscrimination Law

In May President Bush signed into law the Genetic Information Nondiscrimination Act of 2008 (GINA), providing protection for Americans against the misuse of genetic test results by health insurers and employers. Until now, individuals' genetic information has been protected only by a largely untested patchwork of state and federal regulations. According to a poll conducted last year by the Center, 92 percent of Americans are concerned that results of a genetic test could be used in ways that are harmful to them. GINA's passage should allay public fears of genetic discrimination, allowing individuals to take advantage of the genetic tests that are now available for approximately 1500 diseases.

Source: the Genetics & Public Policy Center

specific Disability Program Manager who oversees recruiting, hiring and workplace accommodations for people with disabilities. Disability Program Managers receive specialized training and are considered an important member of each organization. Chris also talked about the federally funded Computer/Electronic Accommodations Program (CAP). CAP assists with evaluation and purchase of adaptive equipment and related services for the workplace. More information on the program can be found on www.tricare.mil/cap. Internship programs for post secondary students and recent graduates with disabilities are another strategy to introduce individuals to the workforce. There are over 7,000 federal internships offered by the Workforce Recruitment Program (WRP) and this opportunity could be adapted by states. See www.wrp.gov for more information.

An employment initiative could also be started by identifying a target population of individuals with severe disabilities, setting realistic departmental or agency level goals for recruitment, retention, and promotion and measuring outcomes. Chris advised a central funding source for accommodation equipment and adaptations. This will help to assure that departmental managers will be less reluctant to spend money on these items, because they would not be taken out their individual budgets.

Commissioner Griffin closed by pointing out that in this state, we are fortunate to have strong support from the current administration for moving in the direction of targeting employment opportunities for people with disabilities. Massachusetts Executive Office of Health and Human Services (EOHHS) Assistant Secretary Jean McGuire reinforced this comment by speaking about the work the EOHHS taskforce on Employment and the Medicaid Infrastructure and Comprehensive Employment Opportunities grant (MI-CEO) are doing to develop the model employer concept in the state. As Massachusetts Rehabilitation Commission Commissioner Carr reminded the audience, with 25,000 jobs among EOHHS agencies alone, this task should not be too difficult to accomplish.

To contact the Employment Now Coalition, e-mail Jim Lyons at jlyons@nilp.org.

OPINION COLUMN

Disability Leadership — Problems and Solutions

By Kevin Wreghitt

For several months now I have been reading *Disability Issues* as the discussion about leadership has unfolded. Paul Kahn encouraged me to write this piece after I expressed some interest in the topic. How could I say “no” to such a friend and mentor, which he has been to me for many years? This is a form of leadership – when someone is endearing to others, causing people to want to honor their requests.

Perhaps Paul was correct when he suggested that, since much has been established in disability rights, youth coming along these days do not see or appreciate what has been done on their behalf. They are like children brought up in the technology age. If one were to take away a child’s computer, he would not know how to function. Quite similarly, if curb cuts, adaptive equipment, accessible housing and PCA services were to suddenly disappear, young people with disabilities would have difficulty coping with their new reality. But people can only relate to what they have been socialized with and are not willing to fight for something they already possess.

There are more explanations which have to be explored in order for the community of people with disabilities to address this problem. It is my impression that the leadership of independent living and the delivery of services have many difficulties. The first is that certain disability leaders who fought so valiantly in their youth and young adulthood became complacent in some respects as they settled into their roles. I never felt welcome in the independent living movement. When I wanted to meet with a disability leader once, he finally gave me a two-minute phone call to brief me on the issue I was interested in, and that was the extent of our contact. I witnessed an independent living project be cancelled in large part because leaders of the two agencies involved could not agree. Over the years I have detected pride and arrogance, probably the result of what these leaders have achieved and the positions in which they find themselves. This pride, however, should not blind the leaders to the consumers they serve, which I am afraid has occurred.

Second, the political atmosphere produces cognitive disconnects between what is done on the leadership level and

what individuals with disabilities perceive publicly. The social and legislative changes are at most times so small that people with disabilities cannot notice their effects or how the leadership influenced the change they are seeing. If the average adult with a disability cannot make the connection between leadership and social improvements, think about what it is like for youth!

The solutions to these problems are various. **First**, all current leaders of the disability community have to look at themselves and think about their own leadership styles and what they individually can do differently. **Second**, disability leadership has to be presented as an exciting and important endeavor. **Third**, leadership programs for youth with disabilities need to be developed in more independent living centers, such as the program that was mentioned at BCIL in the last *Disability Issues*. **Fourth**, experiential components need to be developed, such as independent living internships. **Fifth** and finally, research should be done on what youth with disabilities think about leadership. Perhaps an organization such as the Institute for Community Inclusion could be utilized for that purpose, as well as to develop leadership curricula for youth and young adults.

If we do all this and more, there should be new interest in leadership from the younger generation. I do not mean any disrespect to the present leadership. I only wish to help bring about a resolution to this pressing problem. Perhaps one day our commitment and diligence will conquer it.

Kevin Wreghitt is a person with a disability who has a strong interest in mental health and disability psychology.

He can be reached at ccpboard@verizon.net.



Court Sides with Blind People on Currency Redesign

In a recent ruling a federal appeals court in Washington found that because different denominations of paper money are indistinguishable by touch, the government is discriminating against blind people. The decision could force the Treasury Department to make significant changes to currency, such as printing different-sized bills for different amounts or giving them raised markings. The lawsuit was brought by the American Council of the Blind. The government has been fighting the case for about six years and could appeal the ruling.

Even while fighting the lawsuit, the government has taken some steps to modify U.S. currency for the visually impaired. The redesign of the \$5 bill introduced in March features a giant "5" in purple on one side of the bill to help those with vision problems. The Treasury considered printing different sizes of bills but ran into opposition from makers of vending machines. In fighting the lawsuit, government lawyers said it could cost billions to redesign vending machines, but the court rejected that argument, noting that one proposed solution would be to leave \$1 bills unchanged.

Cambridge City Council Passes Accessibility Ordinance

In March, the Cambridge City Council unanimously passed an amendment to the City's Human Rights Ordinance, requiring businesses to remove barriers to accessibility. This amendment empowers the Cambridge Human Rights Commission to investigate and enforce complaints from people with disabilities who allege that a business has failed to make required accessibility improvements.

Under the new ordinance amendment, Cambridge businesses will be required to remove barriers to access, whenever it is "readily achievable" to do so. Common barriers to access include narrow entry doorways, one-step entrances without ramps, checkout counters that are too high, and parking lots without designated accessible parking spaces. This new ordinance amendment mirrors an accessibility mandate directed at businesses that is contained in the federal Americans with Disabilities Act. All businesses that provide goods and services to the public, known as "public accommodations," are subject to this mandate.

Source: Cambridge Commission for Persons with Disabilities

Disability Issues

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