

# Disability Issues

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Spring 2010

This issue of *Disability Issues* is dedicated to the memory of Editor Paul Kahn, who died at home on January 1, 2010. Paul had served as *DI*'s editor since its inception in 2002. Over the course of his 64 years, Paul had been an editor of several newsletters, most recently *Opening Stages*, an on-line journal for aspiring performing artists with disabilities published by the John F. Kennedy Center for the Performing Arts in Washington, DC. On March 12, Paul was posthumously honored with the BCIL Marie Feltin Award "for his outstanding contributions to the creative arts and disability rights..." He touched the lives of so many, and is sorely missed.

- Ruth Kahn, Acting Editor

## A Revelation

By Mike Ervin

An activist, writer and playwright, Mike Ervin is Paul's compatriot and kindred spirit in Chicago. You can find Mike's writings in the pages of "New Mobility Magazine." He is featured in the film "The Kids Are All Right," which shows how former poster children like Mike feel about certain telethons. This article is reprinted from the "Opening Stages" newsletter with kind permission from the John F. Kennedy Center for the Performing Arts.



Paul Kahn

November 6, 1945 - January 1, 2010

**Paul interviewed me once for "Opening Stages." Here's the excerpt that sticks in my head:**

**Kahn:** Somebody I know said, "Being disabled is being human, only more so."

**Ervin:** That's a good way to put it. That's why it scares people.

It sticks in my head because Paul really nailed a lot with that observation. That explained the baffling fear of disabled folks that persists. Why are some people so desperate to segregate us out of sight or pay us hush money in the form of charity? Why do they feel so threatened and cornered when uppity activist cripples speak up for their rights?

It's because we're just too human. We destroy a lot of their comforting myths about perfection, immunity, strength and autonomy. But that comfort is false, fleeting and fickle, like trying to stay permanently anesthetized by whiskey. The sooner we all stop denying that we're all big bouncing balls of fragility and strength, the better off we'll be. Then maybe we can see the beauty in our reality as humans and not be so freaked out all the time.

This gave me a new sense of relevance and pride in being an uppity cripple. We've got a big important job to do. We're liberating a whole lot more people than just ourselves.

Thanks, Paul, for the revelation.

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## Reflections on a Soldier

By Charles Carr

*Back in the day, Charlie Carr and Paul were among the first pioneers of the independent living movement in Massachusetts. You could say they mastered the art of the mutual admiration society. Paul said of Charlie, "Maybe I could have become independent without Charlie, but his example certainly made it easier. He also showed me that it was possible for a cripp to find the love of a good woman and get married. I rode on his coat tails, and he's been my role model for [over] 33 years." Here is Charlie's tribute to Paul.*

I first met Paul in 1973 at Wellington Hall, a wing of Middlesex County Hospital in Waltham where 15 people with physical disabilities were living because there were no independent living centers or supports in the community. I knew he was coming from home; a nice family, freedom to come and go, and homemade meals. Why would anyone give that up to come here, I thought. It didn't make sense and it would soon become the topic of our first conversation. He explained that it was about his personal declaration

of freedom. It was his chance to go out on his own, as uncomfortable and difficult as it was, to prove to himself that he could do it. As simple as that! I grew to admire and respect him not only for that, but also for his uncanny wit, intelligence and strategic thinking.

Paul could sense the revolution. He knew in his heart and mind that we were on the verge of explosive change. Change that would rock the very foundation of not only Wellington Hall but also the rest of

the country and, in fact, the world. We wouldn't settle for institutional life any longer and fought relentlessly for the rest of our lives to turn the status quo upside down and safeguard our victories as we looked forward to the next battle. I remember Paul saying, "Charlie I'll follow you out of this dump." And he did! Paul wasn't a follower, he was a leader. He became one of the champions of the Personal Care Assistance program and fought every battle to keep it intact and relevant to our needs. Paul also was a pioneer in leading the way for people with disabilities to express our artistic talents and abilities.

His pen, his art and strong commitment to independence at any cost were his mightiest contributions to the movement. He led by example and many followed. Paul Kahn, a gentle giant, an unsung hero and a good friend of mine will be greatly missed but never forgotten.

*Charles Carr is Commissioner of the Massachusetts Rehabilitation Commission.*



Paul Kahn, John Kelly and other activists rallied in October, 2007.

Photo: Gary Devino

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## From the Editor: An Open Letter to Paul Kahn

*Paul Kahn, was a pioneer: he was one of the first PCA consumers, he was one of the first residents of Jewish Community Housing for the Elderly in Newton, and he reportedly lived longer than anyone else with his neuromuscular disability. He was truly a Renaissance man, excelling in drawing, painting, sculpture, feature writing, playwriting and poetry. I was truly blessed to be his life partner, his friend, his spouse.*

Dear Paul,

I'm gazing at a photo of us, taken during the International Wheelchair Dance Festival back in 1997. We're both facing out; I'm slightly in front of you. Sitting in your chrome E&F power chair, you're wearing a blue shirt and black pants. I'm in a black T-shirt and blue pants, standing legs apart, front knee bent, barefoot. My left hand is stretched in back of me, holding your hand as I lunge forward, the right arm extended at my head. We're dancing!

Our life together was a dance: sometimes legato and easy, other times allegro and frenetic, frequently alluring, and always graceful. We had our missteps, our miscalculations, and even an occasional clumsy moment, but we always held each other up, as good dance partners should, showcasing the best we could each be.

You were a prolific artist. As I moved from our apartment into a different unit in this building, I found five portfolios bulging with sketches, drawings and paintings; two boxes of oils and framed drawings; and of course, all the artwork that hung on the walls of our home. You were a prolific writer, with boxes and file folders overflowing with essays, plays, journal entries, magazine and newsletter articles, poetry. Gazing at your "My Documents" computer folder is like exploring



*Paul and Ruth Kahn take a class at the International Wheelchair Dance Festival, June 1997.*

an attic, both discovering and rediscovering treasures. You are with the world and me, always and evermore.

As for your personality, you inherited your father's cynicism, yet you managed to be hopeful. You had a wicked sense of humor. You were a quiet presence, which made your words all the more powerful. Above all, you knew your body. You knew yourself and what you needed more than anyone else. I loved watching you manage your attendants, patiently and directly. You cared for and loved me, empowering me to know you and your ventilator, your wheelchair, your suction machine; empowering me to write, to sing, even to drive!

You also enjoyed a good pun. One day, while I was doing trach care, cleaning and changing the dressing,

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I noticed that your trach collar was a little loose. "Can you think of a nineteenth century French artist who used a ventilator?" I asked. "No, who?" you answered. "Too Loose La Trach!" Suddenly, I remembered other celebrities who had a lot in common with you:

Catheter Hepburn,  
Valve Kilmer, and  
Saline Dion, to name but a few.

I am proud of you, my dear, proud of your accomplishments, including *Disability Issues*. Your work and your life inspired us all.

Let the dance continue...

All my love,  
*Your own Ruth*



*Paul and Ruth Kahn*

## Teaching Tomorrow's Doctors

by Paul Kahn

*In the early part of this Millennium, the Standardized Patient Education Program at Tufts New England Medical Center was founded. Paul was proud to serve on an advisory committee for this groundbreaking program, and was also one of the educators. Today, six consumers with disabilities carry on the work, teaching tomorrow's doctors. In August 2003, Paul wrote this article for "New Mobility Magazine," which has granted permission for its inclusion in this issue of "Disability Issues" in a condensed and edited form.*

Standardized patient education is a teaching method that is widely used in medical schools around the country. A medical student does a mock interview and examination of a standardized patient educator (SPE), who has completed a 12 to 15 hour training program. The SPE is assigned a set of symptoms to describe to the medical student. Then the SPE gives the student constructive criticism on his interviewing skills and knowledge. At Tufts University Medical School, the special twist has been adapting this method to change students' attitudes toward patients with disabilities and to give them insight about how we really live. Begun with a grant from the Massachusetts Developmental Disabilities Council, the project is one of the very few of its kind in the country.

One medical student, who I'll call Anna, admits openly that she has little knowledge about matters that are important to patients with disabilities. "Admitting to not knowing is always a little difficult," she reflects. "You always feel that you are failing your patients a little when you say 'I don't know.' But, in this case, I felt that we were bonding in a way, sharing our weaknesses, and making a commitment to work on the issues together. That was a good feeling."

*Continued on page 6*

# Information Briefs

## Save the Date! Celebrate!

Boston celebrates the 20th anniversary of the **Americans with Disabilities Act** on Monday, July 26 at noon on the Boston Common. The Boston Center for Independent Living, the Disability Policy Consortium and other organizations are planning big-time festivities, so save the date! Don't be late! Stay tuned to the BCIL web site for more details, [www.bostoncil.org](http://www.bostoncil.org), or call 617-338-6665.



The mayor's press release announced that, "The commission will advise the City on policies and procedures affecting the disability community." The Commission usually meets monthly on the fourth Wednesday of each month at Boston City Hall, Room 115, from 5:00-6:30 PM. Call Jay Walsh at 617-635-4316 for more information.

## Housing Search Strategies Workshop

On Monday, April 12, the **Disability Law Center** will present a free training and legal clinic for people with disabilities, their families and advocates. Participants will learn about housing opportunities, housing search strategies, fair housing laws, reasonable accommodation in housing and strategies for retaining housing. Everyone may also sign up for individual sessions to discuss specific housing issues with a DLC staff member. This training session takes place on Monday, April 12 from 10:30-2:30 at the Best Western Royal Plaza Hotel in Marlborough. For more information, visit [http://www.dlc-ma.org/\\_conf/housing.asp](http://www.dlc-ma.org/_conf/housing.asp) or call 508-303-1797.

## Boston Disability Commission Reestablished

Following through on a commitment made to representatives of the disability community, the City of Boston has reestablished its **Commission for Persons with Disabilities**. Nine members were selected in the summer of 2009. John Kelly was elected chair and Carl Richardson vice-chair in January, 2010. The presently-serving eight members are Arnold Berry, Eileen Brewster, John Kelly, Suzanne Leveille, Richard Malley, Carl Richardson, Janice Ward, and Heather Watkins.

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# Spaulding Rehab Opens the Peace Art Gallery

by Timothy Sullivan

Rehabilitation medicine has always had a focus on fixing physical trauma, relearning life tasks and addressing speech and language needs. However, more rehab providers now recognize the need to address

what is often called the “spiritual” side of a patient. One pathway to healing is the arts, which Spaulding Rehabilitation Hospital has embraced throughout its programs incorporating therapeutic recreation and integrative medicine. Triggering new methods of healing and engaging patients in different ways, caregivers have often seen patients

truly thrive while learning or re-learning an artistic skill such as painting or photography. The success of these treatments led to Spaulding establishing a permanent exhibit space, **The Spaulding Peace Art Gallery**, a gallery for artists with disabilities.

“We are so proud to share this amazing art with our staff, patients, visitors and the community. Our

patients make recoveries of all types, and I strongly believe that it’s vital that they are given opportunities to be creative and productive as they often adjust to life as a person with disabilities. This gallery is designed



Artist Richard Mangino and SRH Therapist Jillian Achenback

to be an opportunity for artists with disabilities to exhibit and educate the public on what is possible,” said Oz Mondejar, Vice President of Community Relations for Spaulding Rehabilitation Hospital.

On Friday, February 19th, Spaulding Rehabilitation Hospital’s Peace Art Gallery opened its second exhibit, officially entitled “I Have a Dream,” featuring local artists with disabilities

including two former Spaulding Network patients, Richard Mangino and Luca Ricco. Both Richard, a double amputee, and Luca, recovering from a brain injury, incorporated art as part of their

rehab. The pieces chosen for the exhibit reflect various points in their recoveries and each piece reveals not only their increased function but their changed viewpoint on the world as newly disabled persons.

The gallery, located at Spaulding Rehabilitation Hospital’s

main campus in Boston, will be open through the spring and is open to the public. For directions, visit [www.spauldingrehab.org](http://www.spauldingrehab.org).

*Timothy Sullivan is Director of Communications for Partners Continuing Care and the Spaulding Rehabilitation Network.*

## Teaching Tomorrow’s Doctors - continued from page 5

After having worked with students for a solid 2 1/2 hours, an SPE usually finds herself tired but gratified by the chance to influence future doctors. Occasionally an encounter stands out. For instance, one student was totally nonplussed when the SPE told him that her shoulder pain was limiting her sex life, because the positions she wanted to get into hurt too much.

“His eyes opened wide and his mouth hung open,” the SPE recalls, laughing. “He clearly didn’t know what to do at that point, and let it go without any discussion. When

we talked about it in the evaluation, he learned a thing or two for sure!”

The program raises the students’ general level of disability awareness. A typical statement: “There are a lot of things I never honestly thought about before, like whether people can get on examination tables or access medical machines. I also learned how important it was for people to maintain their independence.” Another student exclaims, “It was amazing to realize that this was the only interaction with a disabled person I have had in four years of medical school. We need more exposure!”

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# Tigers

by Paul Kahn

*Paul Kahn, Renaissance man, was a poet, among many other things.  
He also loved felines of all sorts, especially cheetahs, panthers, Siberian tigers and our own cat, Cairo.*

If I fell out of love with life,  
I would not think that tigers were  
magnificent.

I would not long to hug a tiger,  
to nest my cheek in his furry nape,  
to stroke his massive face,  
and chest to chest to feel  
the thrilling kinship of his breath.

If I fell out of love with life,  
I would not try to paint  
the perfect painting of a tiger.

I would not try to imitate his coat  
with gold and white impasto,  
or mime his stealth with graceful lines,  
or glaze on glaze recall the knowing in his eyes.

No more this aching worship and  
these tributes to the surfaces of things,  
if I fell out of love with life.

Instead a white, cold sleep, a hush of snow  
that flake by flake obliterates  
the edges of desire.

I dread this pall. And yet,  
how long can I remain alive, awake  
when tigers do not come to me to pose  
or offer their embrace?



*Paul explores sculptures at the  
Museum of Fine Arts, Boston*



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