

# Disability Issues

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## Organizations Support Implementation of UN Convention

Recently the United Nations adopted the historic Convention on the Rights of Persons with Disabilities. "Adoption" is when a proposed convention is officially finished and opened for countries to join. At a signing ceremony in late March, eighty countries immediately ratified the convention in an unprecedented show of support for the world's 650 million people with disabilities. "Ratification" is when a country officially decides that it wants to become party to a convention.

Now disability organizations are concentrating their efforts on implementing the Convention. Two such organizations are Disabled Peoples' International and the Fund for Global Human Rights. Disabled Peoples' International, which was active in promoting the ratification of the Convention, has developed the "CRPD Implementation Toolkit." This interactive resource guide at <http://www.icrpd.net/implementation/en/index.htm> will enable people to learn about the Convention, learn about implementation and learn how to design successful implementation campaigns in DPI member countries and regions.

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## Don't Be Disabled by an Emergency: BE PREPARED

by Barbara Ceconi and Kurt Kuss

When an emergency strikes, it is often sudden and frightening. Disasters can range from a blizzard to pandemic flu to a terrorist attack. Although official reactions to emergencies vary, all responses involve taking care of people. However, insuring public safety needs a multi-layered approach, which includes all people initiating a personal preparedness strategy. While we have no control over a potential disaster, we can insure that we are prepared in the event of an emergency – whatever it might be.

Emergency responders may be able to react appropriately in community-wide crises, but no one is as familiar with your and your family's particular needs as you are. It is critical for anyone with a disability to be prepared to shelter at home during an epidemic, or organize a "To Go" kit when it becomes necessary to evacuate your home.

Being able to gather everything you need during a crisis is almost impossible, particularly when you need to act RIGHT NOW! Systematically preparing in advance can insure your safety and, in fact, save your life. For people with disabilities, more planning is important due to the complexity of

needs. It can be daunting to consider all that is involved with organizing and gathering what you might require in the event of an emergency. It can be more difficult if you live alone or have limited resources, but it is not impossible.

If you or a loved one has a disability, it is imperative to utilize the following recommendations. Most of what you need is fairly inexpensive. The one exception is an extra supply of medications. We will offer some suggestions about this later. Remember, you don't have to do or purchase everything all at once. Break down the suggestions into easy-to-accomplish segments. The thing that will help you feel better prepared is to initiate and follow-through.

The pamphlet entitled *Be Prepared, Plan Ahead* was developed by Garrett Simonsen and Lynn Shoefl at the Cambridge Advanced Practice Center for Emergency Preparedness. It states, "Planning ahead for an emergency will give you peace of mind and can help keep your family and friends safe. Here are some simple steps you can take to prepare.



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## Don't Be Disabled by an Emergency - Continued from page 1

- **Family Communication Plan.** Know how your family will contact each other and where you will meet.
- **Food & Water.** Have a 3 day food and water supply for each person in your home. Remember individual dietary needs and plan for your pets.
- **First Aid & Tools.** Have a first aid kit with health products and prescription medicine.
- **Evacuation Kit.** Have supplies ready in your car or in a backpack in case you must leave home. Pack lightly and include basic supplies for 24 to 48 hours.
- **Review.** Every 6 months, review your plans and supplies with everyone in your home. Replace expired food, water and medicine. Update your communication plan."

Keeping an up-to-date medication list costs no money, just time. This will assist emergency responders, whether you are sheltering at home or need to evacuate. Add to the list the assistive devices that you use, for example hearing aids and batteries, charger connections for an electric wheelchair, speech board or voice synthesizer, white canes, supplies for service animals, mobility devices such as canes, crutches and walkers, and other special equipment you might need to take. Realize that you might forget some specifics, or that equipment can get lost or forgotten during a crisis.

You should have a list of all important contact information, including family and friends' addresses and phone numbers who may need to be contacted after a disaster. Compile a contact information list for your physicians and other health care providers in case someone needs to get prescription information or specific medical history. These will be handy resources if you need to evacuate. Also, by including these people in your emergency communication plan, you will begin to develop a network of support, in case you need more help during an emergency.

For people with disabilities, it is vital to self-advocate both prior to and during an actual emergency. If you feel unable to advocate for yourself, speak with your family or members of your support system to insure that your particular needs will be met. Talk to them about your concerns and what services are available in your community during a disaster.

Does your town have contingency plans designed for people with disabilities? For example, if you have a sensory impairment, how will you get the pertinent information? Many communities have a system for dealing with this.

Ask your service providers what their preparedness plans are and how services you depend on might be affected. Are local shelters accessible to you? If not, what other options do you have if you need to evacuate your home?

Discuss emergency plans with your support systems -- family, friends, and medical professionals. Ascertain what your town's emergency plans are and request information about any specific planning for people who have disabilities. You might like to assume that all shelters can accommodate citizens with disabilities, but some emergencies may render the usual shelters unavailable for use. You can obtain some of this information from your local Public Health Department or Board of Health. Most communities have an employee in this office whose responsibility is emergency preparedness. Be patient since many employees may not work full-time. This is another reason to prepare in advance.

Obtain documentation for your service animal from the training center where you acquired the animal. Keep an extra supply of food for the animal in your "To Go" kit and in your home in case of an extended stay.

Contact your health care insurance provider and discuss what your options are for obtaining extra medications before an emergency happens. Many providers such as MassHealth and some HMOs only give you a thirty day supply of your prescriptions at a time. If you refill your prescriptions a couple of days earlier every month, you can begin to gather a few extra days' supply. Presently, planning meetings are occurring on the Massachusetts state level to allow prescription refills of three months during a declared state of emergency. This would require a change in legislation. Make this issue known to your federal and state officials. It is not only a problem for people with disabilities, but for the general public.

A good initial expense is an emergency preparedness kit. Currently there are a couple of pretty good ones available at Target stores and on-line. The Red Cross kit, a nicely thought out package, contains supplies for 4 people, including gloves, ponchos, blanket, flashlight, snap lights, radio and batteries, adhesive and roll bandages, ointments, antiseptic wipes and gauze pads. The cost is \$30, with \$10 donated to the Red Cross until the end of August. Follow this link for details: [http://www.target.com/gp/detail.html/sr=1-1/qid=1179836841/ref=sr\\_1\\_1/601-1652509-2537719?ie=UTF8&asin=B000A3QLBY](http://www.target.com/gp/detail.html/sr=1-1/qid=1179836841/ref=sr_1_1/601-1652509-2537719?ie=UTF8&asin=B000A3QLBY)

A large disaster affects the community as a whole. It does not only strike people who have a disability, but it creates specific areas of concern that may not affect the rest of the population. We have to take as much responsibility as we can for ourselves and those we love.

*Barbara Ceconi and Kurt Kuss are partners in the consulting firm of Access Umbrella, Inc. They have been working on issues of emergency preparedness with the Commonwealth of Massachusetts, Region 4b, which includes the twenty-seven communities surrounding Boston.*

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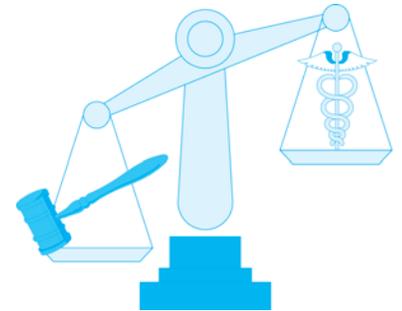
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## From the Editor

In this issue we feature articles about the United Nations Convention on the Rights of People with Disabilities and about barriers to health care. I see the two as related in opposing ways. On the one hand, the United Nations Convention signals a worldwide recognition that we are equal and have equal rights. On the other hand, when we enter the health care system we often seem to go back 50 years to a time when we had no rights. As Karen Schneiderman and Alexa Rosenbloom point out, medical equipment is often inaccessible, architectural barriers continue to exist, and the attitude of providers can be dismissive or paternalistic.

I recently had my own nightmarish encounter with the medical world. Because of a severe stomach virus I had to be hospitalized for a few days. I have a tracheostomy and have been using a ventilator for almost 20 years. So, shortly after getting to my room I was visited by the respiratory care staff. They wanted me to give up my ventilator and instead use one of theirs. Their argument was that, since I was a patient, they were responsible for me. And they couldn't ensure my safety when I was using my own ventilator, because they weren't familiar with it, and it didn't interface with their alarm system. Out of the same sense of responsibility they didn't want my wife to do any of my respiratory care, only hospital staff.



I tried their ventilator but found it uncomfortable. And, since it was new to me, I felt insecure and dependent using it. So, I refused to switch. My ventilator and anyone who is acting as an attendant are functioning as extensions of my body. Through them I am independent and have some control of my life. I felt that the hospital had no right to take that away from me.

My refusal triggered a heated response from the hospital administrators. It became clear that the issue was not so much my safety as it was their fear of liability. I will never forget the ugly scene that ensued when a group of them came into my room at 11:30 at night and tried to pressure me into changing my mind. I wanted to be reasonable and offered to sign a statement absolving them of responsibility for me. But that didn't satisfy them. "What if your ventilator catches fire?" one of them persisted, claiming absurdly that I was posing a threat to the entire hospital. I suggested that they contact my home care company, which leases and maintains my ventilator, to get information that might reassure them about its safety and reliability. I urged them to go online and read up about it. But they kept pushing, showing no compassion for the fact that I was dreadfully sick and exhausted. Eventually I lost my temper completely and started yelling at them to get out. Finally they gave up and withdrew, leaving me shaken and bitter.

In retrospect, I understand to a certain degree the hospital's concerns. But the administrators had no reciprocal appreciation of my rights – the right to function as independently as possible, the right to be treated with consideration and respect, the right to assume the risks I wanted to. Their attitude was paternalistic and oppressive.

## Accessible Paddling Program Offered

This summer Outdoor Recreation of Hopkinton and Spot Pond Boating are running a universal access paddling program for disabled individuals in concert with the Massachusetts Department of Conservation and Recreation and Eastern Mountain Sports. Disabled individuals and their guides, aides and family members can come for supported kayak tours with a certified adaptive paddling instructor. The tours run every Wednesday from 10 a.m. to 4 p.m. at Hopkinton State Park, and every Thursday from 10 a.m. to 4 p.m. at Spot Pond. The program is subsidized by the state, so each participant will be asked to pay only a very small fee. Call Outdoor Recreation of Hopkinton at 508-435-3965 to reserve a spot. You can reserve weekly or for the entire nine-week season. For more information go to <http://rs6.net/tn.jsp?t=iazm74bab.0.unf7q7bab.msaa78bab.7788&ts=S0254&p=http://www.outrechop.com/> \t " blank" [www.OutRecHop.com](http://www.OutRecHop.com).

## Amazon and NFB Join Forces to Promote Web Accessibility

The National Federation of the Blind (NFB) and Amazon.com have announced that they have agreed to work together to promote and improve technology that enables blind people to access and use the World Wide Web. In a cooperation agreement, Amazon.com pledged its commitment to continue improving the accessibility of its web site platform, while the NFB committed to contribute its expertise in Web accessibility technologies to help further Amazon.com's efforts.

"Amazon has always looked for ways to provide the most convenient and easy-to-use shopping experience for all our customers, including those who use screen access software," said Patty Smith, director of corporate communications for Amazon.com. "By working directly with the NFB, which has a wealth of accessible technology experience, we'll be able to make more improvements for both our sighted customers and those customers who use screen access software to browse and shop the Internet."

## Disability Rights Fellowship Offered by ACLU

The American Civil Liberties Union Foundation (ACLUF) invites applications for a two-year Disability Rights Fellowship

with the ACLU's National Legal Department located in New York City. The ACLU is a nationwide, nonprofit, nonpartisan organization dedicated to the principles of liberty and equality embodied in the federal and state constitutions, and in federal and state civil rights laws. The Disability Rights Fellow will work with national and affiliate staff to identify disability rights issues where ACLU participation could make a difference, collaborate with ACLU staff in advocating on behalf of those issues, provide expertise on disability rights, serve as an ACLU liaison with other disability rights organizations, and act as an ACLU spokesperson on disability rights issues. The Disability Rights Fellow will report to a Senior Staff Attorney in the ACLU's National Legal Department and work closely with the ACLU's Legal Director.

Interested persons should submit: a cover letter, a resume, and a writing sample that demonstrates legal or policy analysis. Applications submitted by email should be sent to [hjobs@aclu.org](mailto:hjobs@aclu.org), and the subject line should reference [LGLF-48/WACLU]. Applications submitted by regular mail should be sent to:

American Civil Liberties Union Foundation  
Human Resources  
Attn: [LGLF-48/WACLU]  
125 Broad Street, 18th Floor  
New York, N.Y. 10004

## Massachusetts Begins "Enhanced Adult Foster Care" Program

Caregiver Homes, an approved Adult Foster Care Program in Massachusetts, is now accepting referrals for the new Enhanced Adult Foster Care Program. The program pays family or non-family caregivers to care for an elder or adult disabled family member over the age of 16 at home. Spouses, parents and legal guardians of the elder or disabled adult are not eligible to be paid caregivers. This new program offers the advantage of postponing or avoiding nursing home placements. Clients (the elder or disabled adult) can live with family members and are often happier and more independent as residents of the community.

### Eligibility Requirements

- The client must meet financial eligibility for MassHealth

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- Client needs assistance with three ADLs (activities of daily living) such as bathing, dressing and eating, or assistance with two ADLs and the need for management of behaviors such as wandering, resistance to care and being verbally abusive.
- The caregiver will provide 24-hour supervision assistance with daily activities and other personal care services as needed.

### **How it Works - Steps to become a Caregiver**

All caregiver applicants:

- Start with a telephone interview with a placement coordinator
- Complete an application;
- Agree to allow references checks, including a criminal background check (CORI)
- have a personal interview in your home;
- Allow the recruiter to perform a home assessment to make certain the environment is safe and sound for the participant;
- Must sign a Caregiver Agreement.

The care management team, a nurse and social worker, provides you with ongoing supervision and support. This includes regular telephone conversations and home visits. You will record daily notes about the participant's wellbeing. You will receive general continuing education and specific training as needed to stay current with the changing needs of the participant. All caregivers are required to take occasional time off from care giving. Respite care for the participant is arranged during this time.

### **New International Building Code Eliminates Requirement for Accessibility**

The 2007 Supplement of the International Building Code (IBC) will no longer require apartments undergoing alterations to provide adaptability features to accommodate people with disabilities. Under previous editions of the IBC, an alteration to more than 20 units in an existing building would trigger a requirement for two percent of the units to be provided with basic adaptability features.

A proposal submitted during the International Code Council's (ICC) fall hearings in Orlando, Florida led to the elimination of the IBC's requirement to provide important adaptability features in existing apartments undergoing alterations. Staff from the U.S. Access Board, the U.S. Department of Housing and Urban Development and the United Spinal Association were unsuccessful in a bid to have an alternative proposal requiring minimal adaptability requirements in existing apartments revisited during the ICC's hearings in Rochester, NY in May. The National Association of Home Builders and The National Multi-Housing Council provided testimony against the requirement for minimal adaptability, citing the additional costs and space that would be necessary to comply.

*Adapted from a news release by the United Spinal Association.*

## **EMPLOYMENT NOW Coalition Holds Founding Meeting**

*by Maura Mone*

**Employment Now**, a consumer directed and operated coalition dedicated to systems change and advocacy around employment programs and issues for people with disabilities, held its founding meeting in April at the Morse Library in Natick. Those in attendance consisted of disability rights advocates from around the state and represented a cross-disability group. Also in attendance were staff members from the Medicaid and Comprehensive Employment Opportunities Infrastructure Grant (MI-CEO) and local educational and employment partners.

The group began the meeting with a discussion about what the barriers to employment were and then narrowed the focus to three areas that the group will address in upcoming meetings: the special education system; addressing stigma and attitudes; and transforming state agencies.

In terms of the special education system, the group focused discussion on the skills gap for people with disabilities and identified

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# BCIL and GBLS Launch Project to Document Health Care Problems

by Alexa Rosenbloom and Karen Schneiderman

Have you ever gone to a hospital or a doctor's office for a test only to find that there is no way to get onto the examining table? Have you ever had a medical professional talk to your PCA instead of you? Have you ever been assigned an inaccessible in-patient room when a non-disabled person has the accessible room down the hall?

These are some of the issues that most of us with disabilities have faced at some time in medical facilities across the state and the country. While people with disabilities use health care at a significantly higher rate than people without disabilities, they commonly express dissatisfaction with their health care services. The reason for this fact is fairly simple—in receiving health care, people with disabilities face significant barriers like the ones mentioned above. These barriers are well-documented. In fact, in 2005 the Surgeon General of the United States highlighted the need for action, authoring a *Call to Action to Improve the Health and Wellness of Persons with Disabilities*. The paper called on health care providers to obtain the knowledge and the tools to screen, diagnose and treat the whole person with a disability with dignity.

As a result of this crisis, the Boston Center for Independent Living (BCIL) and Greater Boston Legal Services (GBLS), are undertaking a project to document the disparities in health care between those with and without disabilities. This investigation will cover the needs of people with all sorts of disabilities, and as the project grows we hope to be as inclusive as possible when defining those categories. The end goal of the project is to obtain accessible, high quality health care for individuals with disabilities.

BCIL and GBLS have successfully collaborated in the past, most notably on a 310 million dollar settlement with the MBTA to provide accessible services on subways and buses. As a result of this successful relationship and the comments we received while taking testimonies from disabled people, we discovered the widespread seriousness of the problem of access to health care for most people with disabilities.

The issues that have been brought to our attention are far-ranging. One category of barriers is architecturally related—problems like excessively sloped ramps, narrow doors and hallways, inaccessible bathrooms in patients' rooms, lack of room for wheelchairs in waiting rooms. As one woman stated it, "I end up having to sit awkwardly in the middle of the room or, worse, I have to wait in the hallway."

Another common issue is lack of accessible equipment. While height-adjustable examining tables exist and allow many people to transfer themselves independently, very few are actually in medical facilities. Women are often discouraged from getting mammograms because the machines are not very accessible. Where patients need to be transferred onto an examining table for diagnostic purposes, there is a documented failure to use appropriate techniques. People have reported getting moved by security guards and others who have no training in the process of assisting people with transfers. Some health care workers criticize us for expecting special treatment, when what they really may mean is that they don't know what to do or how to do it.

People with all kinds of disabilities face attitudinal barriers to health care access. Whether it is a doctor focusing too much on a disability and failing to recognize what the real issue ailing a patient is or expecting someone with a disability to do something they are not capable of doing, it is clear that attitudinal barriers are pervasive.

There should be an individualized assessment for every patient with a disability to determine any specialized needs, including diet, bowel program, communication and mobility needs. Oftentimes there is not. Hospitals and doctors offices commonly fail to correctly determine whether a patient needs a modification of policies or procedures. Only a limited number of accessible in-patient rooms exist, and they are often assigned to people without disabilities.

Much as we did with the MBTA project, we can only get a sense of the all barriers that exist by talking to people with disabilities about their experiences receiving health care. We would love to interview anyone with a disability who has encountered barriers like the ones listed above or any additional problems. All interviews will be done in the strictest confidence, and no information will be used without explicit permission from the individual interviewed. Anyone who is interested in participating or would like to hear more about the project can contact Alexa Rosenbloom, 617-603-1564 ([arosenbloom@gbls.org](mailto:arosenbloom@gbls.org)), or Karen Schneiderman, 617-338-6665 x216 ([kschneiderman@bostoncil.org](mailto:kschneiderman@bostoncil.org)).

*Karen Schneiderman is a community organizer at the Boston Center for Independent Living, and Alexa Rosenbloom is a litigation specialist at Greater Boston Legal Services.*



DPI is an umbrella cross-disability organization, established in 1981 and mandated to promote the human rights of all persons with disabilities through full participation, equalization of opportunity and international cooperation. It has national assemblies in 135 countries and Regional Development Offices in five regions -- Europe, Asia-Pacific, Africa, Latin America and North America-Caribbean.

The Fund for Global Human Rights has announced the launch of an initiative on disability rights, a joint effort by an expanding group of human rights donors to increase financial support for organizations working in countries around the world to ensure that the Convention becomes an effective tool in promoting the rights of people with disabilities. Diana Samarasan will lead the development of this new initiative. A graduate of Harvard University, Ms. Samarasan has worked for the American Refugee Committee, Doctors of the World, and, most recently, as executive director of the Mental Disability Advocacy Center. She serves on the Board of the Global Initiative on Psychiatry.

On its adoption by the General Assembly late last year, the Convention became the first human rights treaty of the 21st century and the fastest negotiated international human rights instrument in history. The U.N. High Commissioner for Human Rights Louise Arbour announced the huge level of support at a news conference, saying "It's certainly unprecedented in terms of support for a human rights instrument, but it's apparently setting records for the signature of any convention in the United Nations." Unfortunately for its disabled citizens, the United States did not send a representative to the initial ceremony and has refused to sign the Convention.

The Convention is a 32-page blueprint to end discrimination and exclusion of people with physical and mental disabilities in education, jobs, and everyday life. It requires countries to guarantee freedom from exploitation and abuse for people with disabilities, while protecting rights they already have, such as voting rights and wheelchair access.

The Convention advocates keeping people with disabilities in their communities rather than removing them and educating them separately as many countries do. It guarantees that people with disabilities have the inherent right to life on an equal basis with the able-bodied and requires countries to prohibit discrimination on the basis of disability and guarantee equal legal protection. Countries must also ensure the equal right of people with disabilities to own and inherit property, to control their financial affairs, and to privacy over their personal lives.

Arbour said "it's very appropriate" that the first treaty of the new century "targets a community that has been so marginalized for so long" and that it focuses on rights not just social welfare. She called the convention "a first step" in empowering people with disabilities, stressing that once it comes into force, governments will have to enact legislation and change practices to ensure the rights of people with disabilities. She added that an international committee will monitor implementation of the convention.

According to the latest U.N. figures, about 10 percent of the world's population, or 650 million people, live with a disability, and the number is increasing with population growth. People with disabilities constitute the world's largest minority, and 80 percent live in developing countries, many in poverty.

Yannis Vardakastanis, representing the International Disability Caucus which was in the forefront of the campaign for the Convention, said it represents "a very drastic" shift in the way the international community looks at disabilities. "Indeed and in fact it represents the recognition that people with disabilities should be holders of rights. The 650 million persons with disabilities around the world expect and anticipate that this Convention will change the real living conditions, that this convention will take away the discrimination, the exclusion, and all the obstacles that people with disabilities are faced with in their daily lives."

*Adapted from the International Herald Tribune, the DPI web site and the Fund for Global Human Rights.*

## Subscribe

*Disability Issues* is available without charge to anyone who finds it useful and interesting. To request a print or e-mail subscription, please write to: Center for Health Policy and Research, University of Massachusetts Medical School, 222 Maple Avenue, Higgins Building, Shrewsbury, MA 01545; call 508-856-7857/voice, 866-698-6900/TTY; or go to [www.masschec.org](http://www.masschec.org).

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**Employment Now** - Continued from page 5

barriers that they witnessed or experienced within the special education system. Outreaching to transition age youth and encouraging them to consider employment options early on was an area targeted for action. Discussions around the barrier of stigma centered on the different sources that stigma arises from and how various groups conceptualize the role of people with disabilities in terms of their capacity to work, including family members, employers and people with disabilities themselves. Lastly, the discussion around transforming state agencies focused on facilitating greater collaboration among human service providers and changing how the benefits system impacts service delivery.

The gathering ended with a consensus to continue meeting on a monthly basis. Action plans for the three targeted areas will be the focus of discussions. Contact Jim Lyons or Charlie Carr at 978-687-4288 for more information.

*Maura Mone is a Research Coordinator for the Massachusetts Medicaid Infrastructure and Comprehensive Employment Opportunities Grant at the Center for Health Policy and Research, University of Massachusetts Medical School.*

**From the Editor** - Continued from page 3

As a result of my putting up such a fight the hospital developed a formal, written policy about the use of home respiratory equipment. It was far from what I would have liked, but it at least stated that the hospital would try to use equipment that was identical or similar to the patient's and that there were some circumstances under which the patient could, in fact, bring in his own equipment.

I would advise anyone with similar needs to mine to find out in advance of hospitalization what the institution's policy about home equipment is and advocate strongly for as much autonomy as possible. This is not asking for special privileges. The fact is that people with disabilities have special needs: we only function when we have optimal and familiar technological and human supports. Being ill is stressful enough in itself. We should not have the added burden of having to fight for our security and independence.

*Paul Kahn*

## Disability Issues

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