

Disability Issues formerly Together

Vol. 18, No. 2 a publication of the *Information Center*

Traveling with a Disability

For many years one of the most enjoyable aspects of working at the Information Center was the large number of calls about traveling with a disability. Travel is fun. It is also educational and sometimes necessary, but best of all it is fun. Helping someone plan a trip and providing information that make it easier or even possible to see new parts of the world is also fun. However, at the present moment, the Center is unable to take such an active role in travel issues. Therefore, we offer the following suggestions to make your travel planning easier.

Open World

If you are a frequent traveler you might consider the magazine *Open World* published by the Society for the Advancement of Travel for the Handicapped (SATH). The publication covers travel in the United States and around the world with resources and stories about specific trips. It also covers the programs and meetings of SATH and carries advertising by companies specializing in traveling with a disability. *Open World* is published four times a year and a subscription costs \$13.00 per year. The address is: SATH Publications, Inc./OPEN WORLD, 347 Fifth Avenue, Suite 610, New York, NY 10016, (212) 447-1928. SATH also maintains an Internet website with much travel information at www.sath.org.

This site also contains many useful links to travel services for persons with disability that are well described and frequently updated. It is as good a place to start as any.

Travel is another area in which the Internet is rapidly becoming the best resource for information. If you do not have access to the Internet you can try the public library or your local school for such access or ask a friend or neighbor who is "into" computers to help you search or search for you. Many of the following suggestions are Internet sites. Some of them can be contacted by telephone.

Access-Able

One of the friendliest travel resources for people with disabilities is Access-Able Travel Source in Wheat Ridge, Colorado. Run by Bill and Carol Randall, Access-Able is not a travel agency. Bill and Carol are travelers who want to share their experience. They are dedicated to aiding travelers with disabilities and the mature traveler. They accomplish this by having practical information needed to go across town or travel around the world. The database has not only accessible accommodations, but everything to make a trip fun and exciting. They have information about scuba diving for persons with all types of disabilities. There are accessible safaris, sailing, raft

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Access Expressed Network Debuts

Supported by a grant from the Telecommunications and Information Infrastructure Assistance Program (TIIAP) of the U. S. Department of Commerce, the Access Expressed Network will offer exciting new ways to further Very Special Arts Massachusetts' goal of getting people with disabilities involved in the cultural life of their communities.

Through the Network, People with disabilities will be able to learn about cultural events that are accessible, and cultural organizations will be able to learn about the access needs of their disabled audience. The Network will provide a virtual meeting place where all parts of the community can search for ways of enjoying cultural events by eliminating barriers such as access, admission cost, and transportation. By getting feedback from consumers,

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INSIDE

FROM THE CENTER
RESOURCES
FROM OUR READERS
QUESTION & ANSWER
HOUSING ADVICE

Summer 1998

How to Find What You Need

by Nancy C. Schock, President

It was a pleasure for me to be able to share with you in the previous issue my vision regarding the Information Center and its hoped-for role in enhancing the opportunity for independence and fulfillment in the lives of people with disability. This issue's special message 'From the Center' contains ideas that may be useful to you in seeking your own information.

When exploring possibilities for yourself or a loved one to participate fully in life's activities you need specialized information. People facing disability are often unsure of where to look for this information, or what questions to ask. Furthermore, they frequently do not realize that they can or should be seeking life enhancing information. The issues raised by disability affect so many aspects of life that the range of possible solutions together with the rapid changes being made today present a daunting prospect to those seeking answers.

My first suggestion is to start exploring early with an open mind. You will be surprised at what is available. You can obtain information from many sources, such as knowledgeable individuals, agencies, or organizations, printed materials, the Internet, or by attending meetings or conferences. At some point, in your search, you will benefit from consulting with people who have lived or are living with the same situation as yours in order to learn how they managed. Their solutions may not be right for you, but they will give you ideas of options and alternatives.

The subject categories into which the Center divides all information appear below. Seeing them may help you decide what issues to consider and how to organize the information you find so that it will be most useful to you.

Access\Accommodation	Housing
Communication	Human Relations
Disability [<i>specific</i>]	Information
Education	Law
Employment	Personal Care
Equipment\Assistive Technology	Recreation
Finance	Transportation
Health Care\Treatment	Travel

If you need help deciding what questions to ask, you can think of things in your life that are affected by disability and how you would like them to change. Think positively, assume that there is an answer. You have only to find the answer which works for you. Remember no one person or one organization has all the answers. Persistence is the only rule.

Where to Look

Telephone Book

Your telephone book is a great resource, not just the white pages but the special sections which list community and government services.

Telephone Services

Bell Atlantic, the principal local telephone service provider for New England, is currently preparing a proposal for the provision of Dual Party Relay Service (DPRS). This is the service which facilitates communication between users of TDD/TTY equipment and conventional telephone devices.

Bell Atlantic will be seeking the input of the user community to define what services are most needed and most effective for telephone users who are deaf, hard of hearing, or speech impaired. If you would like to make comments or suggestions, or perhaps be included in the consumer panel determining future DPRS design, you should contact Bell Atlantic's Center for Customers with Disabilities at (800) 974-6006 (v/tdd) or the Massachusetts Commission for the Deaf and Hard of Hearing. If you have had problems finding or using DPRS or have ideas about improving telephone services for this community, this is the opportunity to be heard and to have an impact.

The current DPRS in Massachusetts is reached by calling (800) 439-0183 if you use a voice telephone or (800) 439-2370 if you use a TDD/TTY. When you reach the Relay Service an operator will type the spoken conversation for the TDD user and read the TDD output for the voice user.

Equipment

People who are deaf, hard of hearing, blind, or who have a vision, speech, or mobility impairment may be eligible to receive a TDD, a telephone

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An Essay on Skiing

by Frank Garfunkel - Boston University



Some time ago, several friends asked me to write an essay about my winter of skiing after I had described the experience to them. They were curious about how someone who has severe limitations in the use of his arms/hands and legs/feet (quadriplegia) could ski. They wondered if it was really skiing or was it something else that was called "skiing." I had asked the same question when I found out that there were skiing programs for individuals with disabilities at many ski resorts in New England and throughout the country.

I had assumed that they were for individuals who had normal upper-body strength (arms/hands) which enabled them to use adapted ski poles (outriggers) for balance and for executing turns; that is, poles with miniature skies in place of the baskets and sharp points that are at the bottoms of conventional ski poles. I had also seen individuals with one leg or with a dysfunctional leg and those who sat in sleds with a single ski (mono-ski), who used outriggers to help maintain balance and execute turns. Since I could not handle any kind of ski poles, I had assumed that skiing for me meant being taken down the mountain in a sled that is controlled by an experienced skier who directs and brakes the sled; while this would be closer to real skiing than riding up and down a mountain on a chairlift, it would still miss the essence of skiing - being able to battle the slope by actively controlling speed and direction.

I was also baffled by the logistics; how would I get to the chairlift? How would I get on and off of the chairlift? What would happen if I fell on my way down the slopes?

Thus, I was extremely skeptical when I was told that skiing was possible for the likes of me if I could shift my weight in a specially adapted bi-ski sled -

one with two skies under a frame that permits the skier to sit as one would sit in a row boat, with both legs extended. From this position, apparently, I would be able to shift my weight by leaning left and right; Furthermore I would be able to exaggerate this weight shifting by using my good arm and my legs.

After giving it much thought and then getting on the slopes of Mt. Sunapee for an introductory lesson, I began to realize that as dysfunctional as my limbs were, I could shift my weight in a number of ways; by simply leaning to the right and to the left, by swinging my more mobile right arm to the right for right turns and across my body for left turns. I could also shift my weight by pushing down on my right leg for left turns and my left leg for right turns. If this doesn't make sense, try it. When you push down on either foot you will be able to feel your

weight shifting in the opposite direction. This is easy to write about, but it took many days of skiing to translate the mechanics of weight shifting from my mind to the slopes. What happened is that I had to rediscover the mechanics of skiing for myself. Before my accident I had been skiing for over forty years and I had taught my wife and three children to ski by, among other things, shifting THEIR weights. Now I had to learn about shifting MY weight.

My first attempts were awkward. I often found myself leaning in the wrong direction or leaning and overshifting which resulted in coming to a stop or falling into the snow instead of making a turn. After seven days of skiing spread out over three months at two different mountains, I began to shift by weight and make turns without having to remind myself which way to lean, and which leg to push each time I wanted to make a turn.

Each time that I went skiing I was accompanied by an instructor who skied behind me, at first holding on to the sled and, after two days of skiing, holding on to a six to eight foot tethering line. This enabled her to either brake or redirect me to avoid trees or other skiers. The instructor was critical, not so much because of her instructions, but in the way in which she handled the tethering line. Some instructors would

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Editor: J. Archer O'Reilly III

How to Find What You Need

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Human Services Yellow Pages

A special "telephone" book listing of human service agencies, groups, organizations, and services organized by the groups of people and issues they serve which should be available at your local library.

Government

All states and many cities have at least one office dedicated to the needs of people with disabilities. In Massachusetts these include the Massachusetts Office on Disability, Massachusetts Rehabilitation Commission, Massachusetts Commission for the Blind, Massachusetts Commission for the Deaf and Hard of Hearing, Massachusetts Commission on Mental Health, and others. Call any one of them and ask them to refer you to the resource you need.

Independent Living Centers (ILC)

ILC's are essentially self-help centers that are run and staffed by persons with disabilities. They offer some or all of the following services: attendant care, coordination of personal care attendants, transportation, counseling, information and referral, independent living skills training, and self-empowerment. Most important, you will find people who have faced and understand questions very much like those you are dealing with.

Hospitals and HMOs

Recently the health care organizations have begun to take a more active role in many more areas of health. Your local hospital or HMO are likely to

have a great deal of information on disability, hot lines for information, "talk to a nurse" programs, and a wide range of support groups. Call your provider first and then call every health care provider in your area until you find programs and services that meet your needs.

Disability Specific Organizations

Most major disability related organizations focus on one disability, or perhaps several related disabilities. These national organizations, such as the Multiple Sclerosis Society, usually have local or state chapters which you can contact. They have publications, meetings, and conferences which can provide both resources and networking opportunities. While many concentrate on research and education, others provide direct services to individuals with "their" disability. Do not overlook this resource.

Work

Because of the passage of the federal Americans with Disabilities Act, most employers have assigned someone to be the ADA Compliance Officer. This person can answer many disability related questions and access or refer you to resources. If your, or a family member's disability is affecting your job, talk to your human resource office.

Library

Your library and the librarian are resources. They have books on disability, resource guides, publications of disability organizations, and effective catalogs to help you find them. In addition, today, many can give you access to the Internet where a wealth of information awaits. Many libraries also offer services such as a text readers, large print publication, books on tape, and

captioned movies.

Schools

With new laws and growing awareness the school has become a disability resource. The school nurse, guidance and special education staff can offer information and referrals. Colleges have centers and programs for students with disabilities. You do not have to be a student or have a student in the school to seek their advice.

Internet

The Internet not only has a wealth of disability related information, it may have too much. If you search the Internet with the word "disability" it will take hours just to read the titles of the sites you will find. However, if you have a good browser and ask specific questions you can find unlimited useful resources. One of the nice things about the Internet today is the number of people who love to spend their time "surfing". Don't be afraid to ask even a casual friend who is "into" the net to search for you, more likely than not they will be very happy to have a mission to justify the time they spend "on the net".

Support Groups

There are hundreds of support groups that focus on specific disabilities. They are made up of people just like you, persons with disabilities and their family members. They often have local meetings where people gather to share experiences and information. They can give you the opportunity to ask questions and share solutions. You can find them through the disability-specific organization, the community events section of the newspaper, a local hospital, or the *Human Services Yellow Pages*.

Happy hunting!

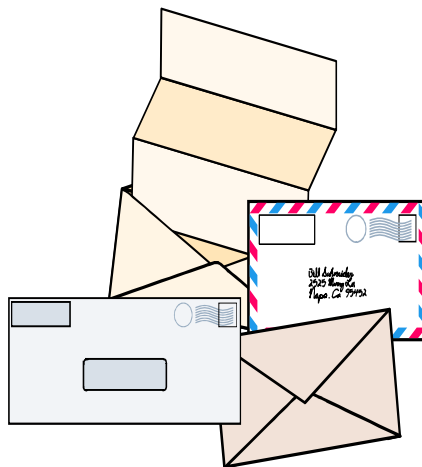
Skiing

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let me ski with minimal interference; others persisted in playing it safe and in overcontrolling me so that I could not ski. I was being taken down the mountain rather than skiing it myself, a possibility that I had anticipated when I first heard about adaptive skiing, as I indicated above.

But, given all of the above, what was it like? How did I feel, particularly after I was able to negotiate steeper slopes, still with a tethering line but essentially on my own? This is where I get into trouble. The usual adjectives do not convey what it was like. Beautiful, exhilarating, awesome, invigorating, inspiring, are all there, but they miss the most salient point. They are words that anyone might use to describe a great day of skiing on almost any mountain. But they lack the context. Skiing, boating, tennis, hiking, banjo picking, carpentry were all part of my life until I smashed my head into the wall of a squash court in August, 1992. This resulted in contusions to my fourth and fifth cervical vertebrae. At the time, and for the next four years, it meant that I could do nothing that required normal functioning limbs, which, or so it appeared to me, was everything. As I thought back about how I spent my time before my spinal cord injury, what I did myself and what I did with family, friends and colleagues, where I went for work and for pleasure, there was an enormous black hole. My mind was inundated by everything that I could not do, places that I could not go, intimacies that I could not share. This led to heavy duty depression, which reinforced that black hole that overwhelmed my perception.

Well, what does this have to do with skiing or with describing how I have thought and felt about skiing? Where is the problem in communicating with readers or listeners about what skiing has meant to me these past four months? Language depends on shared experiences. Part of the experience of skiing is easy to communicate, particularly the beauty of the mountains, the snow and the wind against one's face. But the conversation about physical beauty and the thrill of racing down the slopes pales when compared to the passion of breaking into the black hole that I had been immersed in for all of those four years. It was not the only experience that I have had in the past year that broke into that black hole, but it was substantial. I had developed a cloak of grief that was pervasive and seemingly immutable. This is not a subject to bring up when we talk about the glories of skiing. But it is a perception about the relationship between action and growth. I could not have extradited myself by focusing my attention on my black hole. I had to look elsewhere. It turned out that skiing was one of those experiences that has helped me to begin to extricate myself from that hole.



Question & Answer

Q: Where can I turn for information about camps for children with disabilities?

Joyce, Lexington, MA

A: It is that time of year when kids, and parents, are thinking about camp and it is not any less so for children with one or more disability. One of the Center's favorites is Handi Kids Camp in Bridgewater, Massachusetts. They offer two week sessions for groups of kids with various disabilities and have always received rave reviews. Handi Kids can be reached by calling (508) 697-7557.

For a comprehensive listing of the camps for children with disabilities in Massachusetts you should contact the Federation for Children with Special Needs at (617) 482-2915 or, on the web, at www.fcsn.org.

Q: I have been disabled since 1991. Am I still required to pay excise taxes?

Lewis, South Deerfield, MA

A: If you have a Handicapped license plate in Massachusetts, you may be exempt from auto excise tax. There are specific rules which include the loss of use of two identical limbs or visual impairments. However, this is a local option and the decision is up to your town or city. As with all the financial exemptions, they are not automatic and to get the exemption you must request it from your local assessor's office. If you do not have, or do not qualify for a HP plate, you will not qualify for an excise tax exemption.

The Information Center has a free fact sheet on obtaining Massachusetts HP Plates and Placards. Write the Center if you want a copy.

Travel

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trips, and even a place to learn to sky sail. They include information for persons who are blind about hands-on attractions and about seashore areas with beach wheelchairs. They can be reached at **www.accessible.com** or at P.O. Box 1796, Wheat Ridge, CO 80034, (303) 232-2979. The Internet address is preferred.

Other Resources

Accessible Journeys arrange individual travel plus a wide variety of exotic tours. **www.disabilitytravel.com** or (800) 846-4537.

Accessible Vans of America rents wheelchair adapted minivans in most states. **www.accessiblevans.com** or (888) 282-8267.

Arthur Frommer's Outspoken Encyclopedia on Travel is a general travel site that is very extensive and includes one section for travelers with disabilities and another for seniors. Frommer's has published travel books for people with disabilities including the American Cities book with which the Center assisted. This is a useful site for every travel need and contains much interesting information. **www.mcp.com/frommers**.

Flying Wheels offers wheelchair accessible tours and independent travel. They have specialized in accessible travel since 1970. The president, Barbara Jacobson was the chair of the American Society of Travel Agents' Committee on Travel for Persons with Disabilities. **www.travelexplorer.com/flying/index.htm** or (800) 535-6790.

Global Access, A Network for Disabled Travelers offers first-

hand stories about trips by travelers with disabilities. It also offers travel tips, and more, as well as links to other interesting sites. **www.geocities.com**.

Hidden Treasures Travel serves people of all abilities but specializes in assisting travelers with brain injuries. **www.driveninc.com/~jlyon/hidden.html**.

For information regarding National Parks, availability, accessibility, and accommodations contact the National Park Service. **www.nps.gov**.

In order to have the best possible time on your trip or vacation, you need to invest some time in research. This is particularly true if you are going to new and distant parts of the world. While things have changed markedly for travelers with disabilities in the United States since the passage of the Americans with Disabilities Act, the same is not true in many parts of the world. Accessibility in some parts of the Middle East, for example, means someone willing to carry you up the stairs. The more questions you ask and the more information you review, the better your trip will be.

Telephone

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amplifier, signaler, or other assistive telephone equipment under a program in Massachusetts. To participate you must have Massachusetts residential telephone service and complete an application and Disability Verification Form. Depending on your financial situation, the equipment will be provided free or at reduced rates.

To receive an application package and description of available equipment contact the Center for Customers with Disabilities at (800) 974-6006 (v/tdd).

Delegates with Disabilities

The Massachusetts Democratic State Committee's affirmative action program intended to involve more citizens with disabilities in the electoral process showed its effect at the June 6 nominating convention in Worcester. The support of many delegates with disabilities helped Scott Harshbarger win the nomination for governor on the first ballot.

Attorney General Harshbarger's strong record of safeguarding the rights of individuals with disabilities, including his creation of the Disability Rights Project within his Civil Rights Division and the appointment of an Assistant Attorney General for Disability Rights, earned him the backing of many disability community activists. This support was important because Harshbarger won the conventions endorsement outright by only two votes receiving 50.05% of the total.

A booklet detailing the Attorney General's disability record is available from his campaign and may be obtained by calling (617) 725-1998.

Regardless of where you live you should try to learn what the candidates positions are on disability as well as other issues of importance to you and your family before voting. The decisions made by elected officials often have a significant impact on the quality of your life.

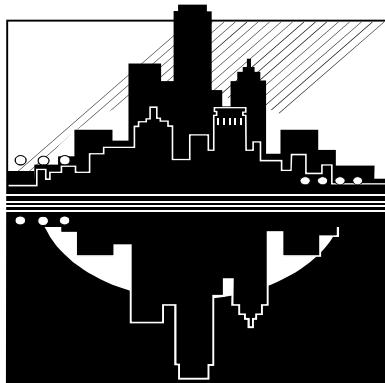
If you are a Democrat, have a disability, and live in Massachusetts you can apply to the Democratic State Committee to be appointed as an affirmative action delegate to the annual convention. Not only is this an interesting way to participate in

Looking for an Accessible Apartment

by Ron Rothenberg

Finding a new apartment is always a challenge. It is harder when you need specific accessibility features in order to live comfortably in that home. The following are a few tips to make your apartment hunting easier and more successful.

- State your needs clearly - use specific terms. Say "I need 18 inches on either side of the toilet," not "I need a big bathroom." Don't be shy when describing why you need a certain feature. Knowing why helps the other person know if the apartment fits. Try to differentiate between "musts" and "would-be-nice" features.
- Be realistic - Few homes are perfect immediately. Make sure the expensive modifications are there - ramping, hallway size, bathroom size - but recognize that doors can be widened and light switches adapted cheaply. Under the



new Fair Housing Law the landlord must allow you to make your own reasonable adaptations.

- Opportunity knocks - Check with your local housing agencies, rehab commission, or independent living center. Landlords often call in search of tenants. Check display ads in the newspaper for the universal wheelchair symbol. This means that there are some accessible apartments in that building. Look for ads in disability-related publications.
- Enlist professional help - Call the office managers of several real estate agencies and ask for an agent who may have experience with wheelchair accessible housing. Speak to several and then choose only one to work

with, so there is an incentive for that agent to find you a home.

- Know your rights - If you encounter discrimination, inform the landlord of your rights in a helpful way - don't be adversarial unless necessary. The rights and needs of people with disabilities are new to some. Many landlords don't know a companion or guide dog isn't considered a pet, or that you're entitled to make reasonable changes to make your apartment more livable. If you don't tell them, they may never know.
- New Construction = More Accessibility (usually) - Most rental housing that recently went into service must have some units built to accessible or adaptable standards.
- Need a lift? - If you live in a high-rise building, it's good to have more than one elevator so that you don't get stranded if one breaks.
- In case of emergency - is there an alternative accessible exit?
- Change of season - When looking at a home in summer, consider the accessibility when there is ice and snow on the ground.

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The **Information Center for Individuals with Disabilities**, as you know, is attempting to reorganize our services. To be successful, we need your participation!

If we are to meet the need - we must raise about ninety thousand dollars. We also need to organize volunteer committees around the state to acquire information, do outreach, and raise money.

We are very grateful to those of you who have already responded. We ask those we have not heard from to send a contribution and commit to an exciting opportunity today.

Yes, I want to be a part of the "Re-Birth" of the Information Center.

Please accept this donation of \$ _____. Please count on me as a volunteer. _____

Name: _____

Address: _____

City/Town: _____ State: _____ Zip: _____

Telephone: _____ (H) _____ (B)

Information Center

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Access Expressed

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cultural organizations will know better where to direct their often scarce resources. For instance, they can find out from people with deafness what events interest them most and provide more sign language interpreters for those events.

The Network will also be able to enhance the cultural experience of people with disabilities by providing certain services. For instance, prior to attending a performance, a person with blindness could access an on-line playbill for use by text reading software.

Information will not be confined to Massachusetts, but will gradually incorporate data from linked sites in 24 other states. In each state the site will be developed by a team that includes the local Very Special Arts affiliate, the state cultural council, the state or municipal office on disability, and a consumer organization such as an independent living center. The state sites will be added incrementally, and as of now an initial eight will have joined. They are

Maine, New Hampshire, Georgia, Michigan, Ohio, Virginia, and Washington, DC, and Washington state.

Very Special Arts' partners in developing the Network are the Massachusetts Cultural Council, the Massachusetts Office on Disability, and Millennium Productions.

The address of the Network is **www.accessexpressed.net**.

Try it today if you have access to the Internet or try a public access site like the school, library, or New England Index. Don't let the lack of a home computer keep you off the Internet and away from all the useful information you can find there.

Delegates

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the process, it is also an important way to insure that the issues of concern to our community are given due consideration in the political life of our state. Delegates are chosen between February and May each year.

Housing

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● How's the neighborhood? - Check out curb-cuts and access to stores and transit in the area.

● Can we park? - Is there HP parking nearby? Does your vehicle fit into the garage. Some raised-roof vehicles can not fit into standard garages.

● Chose carefully! - Unless you're in a bind, take your time and find a home that is right for you. Don't let initial discouragement trap you in a home that will send you out looking again soon. If you are happy with the home, consider a long-term lease.

● Finally, once you have found a unit that suits you, be kind to your landlord - Though accommodation is the law, it's nice to receive a few, strokes for being a good, accessible landlord. If there are other vacant accessible units, let people who need them know. If accessible homes were always rented, more would be built.

*Ron Rothenberg is a Trustee of the **Information Center** and a Realtor with specific expertise in accessible housing for both rental and ownership.*