

Disability Issues

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Working from Home Resource Guide

NOTE: There are lots of "Work from Home" scams you may encounter in classified ads, on the Internet, and in spam e-mail. Most of these "business offers" promise great monthly income, but ask for cash up-front to bankroll a "starter kit." Don't send money to any of these come-ons without verifying their legitimacy with the Better Business Bureau and/or your vocational rehabilitation counselor. Before trying to start your own home business, get some good counseling to develop a sound, workable business plan, and realize that the failure rate for start-up businesses is more than 90 percent. The accompanying article in this issue does not deal expressly with self-employment or home business per se.

Where to get Assistive Technology (AT) Help:

Massachusetts Rehabilitation Commission
Assistive Technology Program
Tel: (617) 204-3851(voice) • (617) 204-3815(TDD)
Fax: (617) 727-1354

E-mail: Karen.Langley@MRC.state.ma.us
www.mass.gov/Eeohhs2/docs/mrc/atp.rtf

Spaulding Rehabilitation Hospital Assistive Technology

Contact: Peggy Dellea, MS OTR/L
Tel: (617) 573-2927
E-mail: mdellea@partners.org

ABLEDATA - Product Resource
Tel: 1-800-227-0216 www.abledata.com
Job Accommodation Network,

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The Pleasures and Perils of Working from Home

by Raymond E. Glazier

With the proliferation of personal computers and advanced communications technology, "telecommuting" is becoming ever more common in corporate America. There are special advantages to both employees with disabilities and their employers to telecommuting as an eminently reasonable job accommodation. An exclusively from-home worker saves the employer overhead operating expenses associated with giving that employee onsite office space, utilities, etc. For office workers like yours truly, one big bonus is eliminating the to-and-from the worksite transportation headaches, such as less than reliable paratransit van service. And in a meeting with a new business client via a conference call, unless it is a videoconference, the client's feelings about disability don't come into play. (This is not true for persons like myself

whose speech impairment is more of a career impediment than my wheelchair.)

Many employers, like mine, are already accustomed to the notion of telecommuting by workers on travel assignments or during episodes of illness. So, they are likely to be amenable to hiring and retaining employees with disabilities by providing policy flexibility and technology for the purpose of working from home. While you need not disclose the need for this in a job interview, you may want to feel out the employer's experience with the concept. You can then, once the job offer is made, disclose the nature of your disability and how it will affect the manner in which you perform essential job functions, and, if pertinent, ask for telecommuting as an ADA reasonable accommodation under Title I. (If you don't specify the needed accommodation at this point, you may lose your right to it.)

In instances where the technological means for telecommuting or home business self-employment are an undue financial burden to either the employer (for example, a very small business) or the worker, the state-federal vocational rehabilitation system (the Massachusetts Rehabilitation



Ray Glazier at work in his home office

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Commission in our state), the Veterans Administration, state agencies for the blind or for the Deaf are often able to provide equipment, including assistive technology, to facilitate competitive employment or self-employment in the home office setting.

There are a number of other perks and advantages to working from home:

- 1) No one knows that you're in your pajamas or just out of the shower;
- 2) If you need help with personal care tasks, your home PCA doesn't have to travel far to provide on the spot help as needed;
- 3) For the most part, you can more easily schedule your work time so that it meshes well with your individual biorhythms, personal preferences, and other commitments;
- 4) It is easier to multi-task, for example, keep a watchful eye on a napping child or a toddler in a playpen while you are working;
- 5) The kitchen and bathroom are close at hand;
- 6) You're available to answer the door to take a delivery or admit a repairperson;
- 7) And you're right there for household emergencies. (I won't soon forget the time a neighbor phoned me at the office to tell me that voluminous black, smoke billowing from the chimney of my house, had brought the Fire Department to the scene, and they had already broken down the cellar door to turn off my oil furnace which had run amok.)

So, I was not totally bent out of shape when a new secondary disability made it necessary for me to curtail my work hours and give up the daily trek to and from the office. I already had some of the basics of a home office that I had been using for personal business and after-hours work. My employer had provided the requisites for telecommuting on permanent loan: a laptop computer, a full-size flat screen monitor, special mouse, and special keyboard, plus software that allows me to work from home on my office desktop computer like *The Invisible Man*. A colleague who came into my office to find a hard copy document she needed for the project we are working on together nearly lost it when she saw the phantom Ray composing an inter-office e-mail from home on the desktop's monitor, letters dancing onto the screen.

My MRC counselor had procured a small, portable voice amplifier through MRC's Assistive Technology program. My health insurance funded on-site assistive technology assessments by a skilled occupational therapist from Spaulding Rehabilitation Hospital; she hooked me up with Verizon's little-known AT program for phone service customers with

disabilities who need specialized equipment. A PCA and a friend doubled the counter space of my home desk setup by adding another 8-foot section of kitchen countertop, supported by two second-hand file drawers raised to the right height by slipping old cinderblocks under them. I was all set, it seemed, for the best of both worlds.

Now, six months into working from my neat home office, I can report back on the perils of working from home, including those that initially fell into the "pleasures" column:

- 1) It can become very psychologically isolating without face-to-face interaction with colleagues in the workplace, if you envelope yourself in a cocoon within those four walls. It's best to schedule social activities that get you out of the house once a day. (See also # 5.)
- 2) There can be too little separation between the professional and the personal. The phone rings constantly with telemarketers from Bombay named "Bob" or "Ken," trying to sell mortgages or vinyl siding. Getting caller ID helps. But you have to answer the phone, because even calls from "Unknown Caller" may be colleagues calling in on their cell phones from remote locations. Or, the boss may call during your peaceful lunch break, because you are more accessible to discuss the latest project crisis than if you were chatting with friends in the cafeteria.
- 3) Speaking of food, the kitchen is in the next room, so snacking during the day doesn't require the effort of taking the elevator to the vending machines on the next floor, which makes mindless eating too convenient and seemingly low-cost. (*Weight Watchers*, here I come.)
- 4) Sitting at my computer in my sweats somehow just doesn't put me in the proper frame of mind for writing research reports. Some days I feel the need to dress in office attire (minus the tie) just to get fully into the serious work groove.
- 5) Upon returning recently to my employer's offices after an extended absence, there were new faces I didn't recognize, who looked back at me with the same questioning eyes, "Like, who is that guy in the power wheelchair?" Now I try to make an appearance there at least once a week, just to remind everyone that I do exist, and not only as a phantom in cyberspace.
- 6) As I approach the preparation of my income tax return, now the IRS tells me my home office isn't a legitimate deduction, because the room also has my bed and my TV in it; the space isn't totally dedicated to income-producing work activity. But I never had to prove before that my "real" office activity was 100% productive. Go figure...

Raymond E. Glazier, Ph.D. is the part-time (mostly from home) Director of the Abt Associates Center for the Advancement of Rehabilitation and Disability Services and a member of the Disability Issues Editorial Board.

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Raymond E. Glazier



From the Editor

In this issue we focus on two poles of experience. Ray Glazier and Fred Fay show us how much we can accomplish while staying at home, and, in contrast, Kristy Lacroix paints a picture of how enriching it is to roam the globe.

Both are equally valid ways of interacting with the world. But please notice that neither Glazier nor Fay stay at home by choice, but rather by necessity. The convenience and the ease that technology offers are marvelous, but we should not be seduced by them into laziness or misled into thinking that an experience filtered through technological devices is the same as a direct one. Think of the difference between a face to face encounter and an e-mail exchange. The e-mail transmits some meaning but is totally lacking in the subtleties conveyed by facial expression, tone of voice and body posture.

And for people with disabilities this very anonymity offered by technology may pose an unhealthy temptation. Yes, we can hide our disabilities on the Internet, but that doesn't do anything to challenge the shame and self-consciousness that might burden us or change society's negative attitudes toward disability.

Let's always regard technological means of communication as tools: the goal is full and equal participation in the world.

Paul Kahn

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Office of Disability
Employment Policy
U.S. Department of Labor
800-526-7234 (V)
877-781-9403 (TTY)
www.jan.wvu.edu/

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People with Disabilities**
U.S. Department of Labor,
Small Business and Labor
[www.dol.gov/odep/programs/
promotin.htm](http://www.dol.gov/odep/programs/promotin.htm)

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& Social Services fact sheet
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case_management.pdf](http://www.mass.gov/Eeohhs2/docs/mcdhh/case_management.pdf)

Contact by Videophone
Boston Office: Dial 617-265-8447
or use the following IP address:
70.22.152.162

Springfield office: Dial 413-737-8691
or use the following IP address:
70.109.254.98

Assistive Technology

for the Blind Program
MA Commission for the Blind
MCB Boston Office
48 Boylston Street
Boston Ma 02116-4718
Tel: (617) 727-5550
1-800-392-6450 (MASS. ONLY) Voice
1-800-392-6556 (MASS. ONLY) TDD
Fax: (617) 626-7685
www.mass.gov/mcb



Find out how
to travel the
world!

See story
on page 7.

Fred Fay: A Nationwide Reach from Bed

interviewed by Paul Kahn

KAHN: You recently won an award from the American Association of People with Disabilities. Can you tell me about that?

FAY: There's a big trophy over there on the shelf. It was kind of strange. I had started **Justice for All** along with Justin Dart and Becky Ogle. And I also started the **American Association of People with Disabilities** with John Kemp and Paul Hearne and Justin. The award was presented by AAPD for outstanding leadership in disability life. It was actually given by Andy Imperato of AAPD to Yoshiko Dart. She's a dear friend. We worked together on a lot of stuff with Justin. Yoshiko gave the award to me. It's the first re-gifting of an award I've ever heard of. She said she wanted to honor my leadership. I was amazed. There was a formal presentation with Commissioner of Mass. Rehab. Commission Elmer Bartels, and Executive Director of Northeast Independent Living Center Charlie Carr, and Executive Director of the Boston Center for Independent Living Bill Henning, and photographer Scott Cooper. It's really weird to get an award from an organization you started.

KAHN: You've gotten a lot of other awards, too, over the years like the Henry Betts Award, haven't you?

FAY: I guess I get about one award a year, on average. The one that I'm most proud of is one that has been received by Elvis Presley, Darth Vader, Henry Kissinger, President Kennedy, President Nixon – all selected when they were under age 36. It's from the United States J. C.'s (Junior Chamber of Commerce). They pick out 10 people each year. That was quite an honor to be up there on the stage with the others.

KAHN: You've also been instrumental in founding a lot of organizations. How many do you think?

FAY: About 15. It seems wherever I go I wind up getting involved in an issue and organizing people to deal with it, going all the way back to the Washington Architectural Barriers Project to make the subway system there accessible. Then Opening Doors, providing peer counseling to the newly disabled.

KAHN: That's when you were first disabled, right?

FAY: Yes, I was 16 when I fell from a trapeze in 1961. It was something I had in my backyard all my life. I'd "skin the cat" where you hang by your hands and swing your legs. I remember the four-letter word I said as my hand slipped and I hit the ground right on my forehead and ended up in the hospital. I went from the local hospital to the National Institutes of Health and received about five weeks of acute care, and then went down to Georgia to the Warm Springs Foundation, the place Franklin Roosevelt went.

KAHN: But you've been dealing with more than a spinal cord injury.

FAY: Yes, for 20 years I was up and around in a wheelchair. And then I had a cyst in 1964 that eventually filled with fluid, and I lost sensation going up the side of my arm. They operated on that and fixed it for a while. And then about 20 years later it started up again, and they put in a shunt to drain the excess fluid. Finally, I ended up getting to the point where, if I raised my head up or sat up, I'd have difficulty breathing and swallowing. So, I stay horizontal pretty much. I use a power wheel bed. It lets me get around to a limited degree. I was flat on my back for about four years before I figured out how I could create a mobile device.

KAHN: Is this custom-made?

FAY: Pretty much. Paul Corcoran (co-founder of the Boston Center for Independent Living) helped me do the first one about 20 years ago. I went to a rehab place on the South Shore, and I spelled out exactly what I needed and showed them a computer-assisted design illustrating exactly what I wanted. The company that makes Bounder wheelchairs has recently begun making something very similar to what I have. So, I ordered this second one from them. It works really well. It's got a bunch of tricks. There's a real loud horn that I'd show off, except it would wake up Trish (Fay's wife) and the neighbors. It's got a two-speed fan and headlights.

KAHN: Do you get out of the house with this?

FAY: Yes. We figured out a way to transfer from the back of Paul's or

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Fred Fay

University of Washington Announces Summer Computer Program for Deaf and Hard of Hearing

Advancing Deaf & Hard of Hearing in Computing (ADHHC) is a project of **The Alliance for Access to Computing Careers** (AccessComputing). The program is for deaf-blind and hard of hearing students at least 18 years old and ready to enter their college freshman, sophomore or junior years. A goal of the project is to increase the participation of individuals who are deaf or hard of hearing in computing fields.

The program:

- 9-week program, from June 17 to August 17, 2007
- Tuition, room/board and transportation to Seattle are FREE
- Students will take UW courses for college credit (e.g. Precalculus, Data Structures, Introduction to Programming)
- Group project in animation or other computing field
- Activities in the Deaf community and tours to local industry such as Microsoft, Google, Adobe and others)
- Meet successful deaf & hard of hearing role models in the computing field
- Enrollment limited to students accepted through an application process University of Washington
- Located in Seattle, WA, home of America's software industry

For more specifics about the program log on to www.washington.edu/accesscomputing/dhh

*Adapted from Access to Computing Careers,
University of Washington*

Assistive Technology News Launches News Web Site

Assistive Technology News has launched www.atechnews.com to assist the nation's 56 million people with disabilities stay abreast of assistive technology products that enhance their independence and improve their quality of life. This dynamic web site includes everything people with disabilities and their loved ones need to know, from new product announcements, to advocate profiles, to product evaluations, to interviews with leaders in the public and private sectors working on disability issues, to policies that impact people with disabilities. There will be columns on Aging and Technology and Medicine Behind the Scenes, articles about users of assistive technology

products, columns on AT products and profiles of AT leaders. This service ATN is launching responds to the tens of thousands of e-mails, faxes and calls it has received over the last decade. "ATechNews.com will be the site to visit to learn about assistive technology products and disability issues," says John M. Williams, the founder of ATechNews.com. Williams, who coined the phrase "Assistive Technology," has been writing about disability issues since 1978 and about Assistive technology products since 1980.

An asset to the site will be a column by Dr. Richard Pellegrino on Medicine & Technology. "I am pleased to be associated with ATN's efforts to report on policy issues related to Medicine & Technology," says Dr. Pellegrino. The doctor believes consumers need to know what drives rising medical costs and how technologies and government policies can bring these costs down.

Disability affects every family in the country. It impacts them personally, financially, physically and/or psychologically. Assistive technology products lighten the struggle of families dealing with a family member with disabilities, and they eliminate historical barriers that prevented people with disabilities from living independent and productive lives.

Adapted from Assistive Technology News

Boston Ballet's Adaptive Dance Program Honored

Boston Ballet's Adaptive Dance Program was honored by the Massachusetts Down Syndrome Congress (MDSC) with its **Allen C. Crocker Award of Excellence**, in recognition of the program's continued work with children with Down syndrome. The award is presented annually to a person or group that celebrates the excellence of people with Down syndrome and significantly contributes to improving their quality of life. It was established in 1994 in recognition of Dr. Allen Crocker's many years of nurturing individuals with Down syndrome and their families throughout their life's journey.

Boston Ballet's innovative Adaptive Dance program provides a positive environment for children with Down syndrome to learn movement and focus skills. In partnership with The Department of Physical Therapy, Children's Hospital, Boston, Adaptive Dance was founded in 2002 and is designed to expose students to a curriculum that aids in the growth of self-confidence and self-esteem. The goal is for participants

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Trish's station wagon. I slide in, and this tows behind me. I went to visit my son in New Hampshire where he's going to college, and up to Vermont, and to a friend's who has 150-acre estate up in Maine, and out to Nantucket. I don't travel a lot. Maybe a half-dozen times to receive awards.

KAHN: Seems like a good reason to get out.

FAY: And then recently to MGH (Massachusetts General Hospital), because I had bladder cancer. They did biopsies that showed I had a tumor inside the bladder, stage two. I went to MGH to the best urologist I could find, and he removed the bladder completely. Apparently they got everything.

KAHN: That's great. I want to concentrate now on the assistive technology that you use. Your bed is mobile. What else does it do? I see it raises and lowers and tilts like a wheelchair.

FAY: And it has a kill switch for everything. And head lights. And three different speed settings and three different torque settings that are all variable, so it's easier to get over steep things.

KAHN: What other technology do you use?

FAY: I have about 45 things on remote control. (Pointing) This lets me control the VCR, DVD, TiVo, high definition color TV, etc. out in the living room. It also has environmental controls: when you came in I opened up the skylights. If you back up, I can show you what's what. This one is from Radio Shack, believe it or not. It controls 16 devices. The doors open and shut. A whole bunch of different things operate —skylights, house lights, fans, the air conditioner and heater. What else? Gosh! —the outside lights. If I hit a button here, the flames in the fireplace pop right up. When I was flat on my back for the first time, I wanted to have as much as possible within reach. That saved my life!

KAHN: You have the TV tipped upside down.

FAY: Yes. I'm looking straight up in the air toward the ceiling with the monitors in between. I can pull out plexi-glass shields so, I can put reading materials up here and read through the glass. The keyboard I park on my chest.

KAHN: Do you use a voice recognition system?

FAY: I do for dictation and stuff. It's standard Dragon. I love Dragon! It took me forever to get used to it. I was one of the beta testers for the first version of Dragon Dictate 1.0. I gave them three pages of very critical feedback. It was definitely not ready for prime time. That was about 15 years ago. I've done a lot of beta testing over the years on software and hardware products. They usually give you the product free if you test it out. That's been wonderful! Let's keep going here.

The battery charger I can do myself, so I don't need somebody else. There's a white cord that I plug in at night.

KAHN: You charge the wheel bed?

FAY: Everything. And then I've got a radar tuner-receiver, dual-deck cassette deck and CD changer. I can use a printer, fax, etc. My suction machine is on the shelf near the C-PAP (continuous airway pressure machine). In recent years, I've had less sleep apnea. My oxygen saturation used to be 55. I'd wake up in the middle of the night, just gasping for breath with a pounding headache and heart racing. That was scary.

KAHN: I'll bet. So, technology keeps you alive, too.

FAY: Yes, I have the C-PAP for breathing. And with the cough assist I'm able to cough on my own and not get pneumonia, which I almost got a couple of times.

KAHN: That must be a danger, if you're lying down all the time.

FAY: Yes, I'm on my side for about 20 minutes a day total.

KAHN: What do you think the most important advances have been in assistive technology for people with disabilities in the last 20 years or since you became disabled yourself? What has made a difference in your life?

FAY: Trish! She's right up there on the list. I think very early on, shortly after breaking my neck, realizing I had the freedom to choose how I viewed my situation. That philosophical insight made life a lot easier. I think what I've learned from other people with disabilities has been incredibly helpful, whether it's been peer counseling or just bullshitting on various topics.

KAHN: Can you talk more about on the ways that assistive technology has been important to people with disabilities?

FAY: Gosh. There are so many. For me, just to be able to go from one height off the ground to another height a couple of feet up – books on the bookshelves I can reach. That alone is really helpful. Technology has helped decrease the gap between able-bodied people and people with disabilities. From an advocacy point of view, we've been able to change public policy. Technology has been incredibly helpful for sending out alerts. It used to take a week or two to send out a newsletter. And by the time you got the information out, the vote had already been taken. I was Chair of Americans with Disabilities for Clinton and Gore. We won two huge elections! As we move from typewriters to computers to modems to fax machines to e-mail to who knows what, there's an incredible increase in productivity. How else can I reach 3500 people in just a few seconds with the Justice for All list serve without ever getting out of bed? It really is mind-boggling. We send out literally millions of e-

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Information Briefs - Continued from page 5

(aged 6-17) to develop an appreciation for dance and music and to improve their movement patterns, while increasing focus and creativity. The program has grown from one class of 11 children to four classes with a total of 42 students.

For more information on Boston Ballet's Adaptive Dance Program log on to www.bostonballet.org.

Adapted from the Boston Ballet website

President Signs "The Combating Autism Act of 2006"

President Bush recently signed **The Combating Autism Act of 2006** authorizing expanded activities related to autism research, prevention and treatment through 2011. Autism, sometimes called "classical autism," is the most common condition in a group of developmental disorders known as the Autism Spectrum Disorders (ASD). There are more than 1.5 million cases of autism in the United States. The Act authorizes research under NIH to address the entire ASD.

Specifically, the Act authorizes Regional Centers of Excellence for ASD research and epidemiology. These Centers collect and analyze information on the number, incidence, correlates, and causes of ASD and other developmental disabilities. The Act also authorizes grants to States for collection, analysis, and dissemination of data related to autism. In addition, it authorizes activities to increase public awareness of autism, improve the ability of health care providers to use evidence-based interventions, and increase early screening for autism.

For more information about ASD and local chapters go to the Autism Society of America web site www.autism-society.org

Adapted from the White House Fact Sheet on Combating Autism.

Wheeling around the World

by Kristy Lacroix

I gained my experience with obstacles faced by the mobility challenged traveler from traveling with my husband, Jerry, who has multiple sclerosis and uses a power wheelchair. We started traveling over thirteen years ago and ran into many challenges. "A vacation should NOT consist of challenges, but of a good time to be remembered," I kept saying. I use to think, "Someone has got to do something about this." So, I started taking notes, photographs and even a couple of videos of accessibility. Five years ago, I took the leap and left my twenty-two year career selling office products and opened Wheelchair Escapes.

I am a Certified Accessible Travel Specialist (The Travel Institute), an Accredited Cruise Counselor (Cruise Lines International Association) and a member of SATH (Society for Accessible Travel and Hospitality). I attend the SATH World Congress each year to stay abreast of the ever changing accessibility throughout the world.

People with disabilities should not be intimidated from traveling. Jerry and I have visited most of the Caribbean islands and found wheelchair accessibility in many places. We have a list of ports with accessible vans.

Our next major trip is a twelve day Scandinavia/Russia cruise in 2008. We like to check out the accessibility first hand and enjoy ourselves while doing it. We always welcome others to join us. We have had many first time cruisers travel with us. We know that takes away a lot of the first timers' concerns. Just remember, accessible cabins are limited, so it pays to book early.

You can learn how to pack your power chair for airline travel. You can get an aisle seat with an arm that rises for easier transfer and also get the visuals to go with it and learn how to use them. My business and pleasure is helping people make all of those necessary arrangements.

More and more the world is opening up. If you need a wheelchair, a scooter or a hooyer lift delivered to your cabin or hotel room, it can be arranged. If you want an accessible van waiting for you at the airport, that can be arranged, too. Sometimes, you can even get a PCA (personal care attendant) to travel with you.

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mails. I'm doing stuff I never would have dreamed of without a lot of the technology.

KAHN: We've been able to be political movers and shakers because of technology.

FAY: I just think back to when I first got my rehab counselor from Vocational Rehab in Maryland and he posed that instead of going to college, which is what I fully intended to do, that I join a sheltered workshop. Somehow I managed to convince him that there was a little greater potential than a sheltered workshop. I'd love to see him now!

KAHN: What new technology do you think is looming?

FAY: There is so much coming, and it will be here soon. One of the latest things I've gotten is a camcorder video camera. With this I can play Scrabble with my mother and my son over the Internet, and we see each other and talk back and forth as we play. It's just really cool to be able to do stuff like this, to be able to see my siblings and my grandchildren and so forth. It's an incredibly exciting time to be alive!

Wheeling Around the World - Continued from page 7

Cruises are my specialty. This past summer, we spent almost two weeks exploring the accessibility of Alaska. Jerry's favorite was the wheelchair accessible helicopter ride over Denali National Park. He had ridden in many helicopters while in the Navy, but this was the best. Once we were seated in the helicopter, the pilot gave out headphones. The beautiful, soothing music of Enya played in our ears. Imagine soaring over Alaska's famed Denali National Park, viewing sparking rivers, winding glaciers, grizzly bears, Dahl sheep, a herd of caribou and the rich colors of the Alaska terrain. If you are REALLY lucky, a bird's eye view of Mt. McKinley awaits.

The day we spent in Glacier Bay was extraordinary. Imagine viewing a glacier that has wound its way 123 miles to greet the bay. The diameter is one mile across. It extends upward 250 feet and 100 feet below the surface. Seeing that rich, turquoise color in the ice and the glacier calving was awesome. What a sight!

I really want to encourage people to think out of the box. Where do you want to go? With some experience on your side more is possible than you can imagine. There are even accessible African Safaris!

You can visit Kristy's web site at www.wheelchairescapes.com or call her toll-free at 866-382-3596.

Disability Issues

Center for Health Policy and Research
University of Massachusetts Medical School
Higgins Building
222 Maple Avenue
Shrewsbury, MA 01545

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