## No.1/September 2010

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### **CHALLENGES**

In August, over 1,000 amputees, families, and **supporters came together** for the Amputee Coalition of America National Conference.

# Strength through accessibility

t the conference, amputee surfers taught surfing classes. Amputee lron Mantriathlon winners addressed mobility clinics. The latest, state-of-the-art computerized arms and legs were demonstrated. And, there were countless stories of tragedy and recovery. What we heard is that access is the key to resiliency.

This year, we celebrated the 20th anniversary of the Americans with Disabilities Act (ADA). Transit buses now provide lifts for people with physical impairments. New construction includes accommodations for those with disabilities. Sidewalks are built with wheelchair ramps. The ADA has transformed our physical environment, our attitudes, and our disabled population's potential for success.

We live in remarkable times. New technologies and strategies are turning the once unimaginable into reality. These developments clear a path from the laboratory to children and adults awaiting safe and effective treatments and devices that enable them to live

bountiful lives.

This crossroad between science and technology is largely made possible through the research and development investment for our wounded warriors. Almost every war has given rise to medical achievements like penicillin, the method for large-scale blood transfusions, and even medical evacuations by helicopter. Today, the Department of Defense is asking civilian researchers to create prosthetic and mobility devices that far out-strip anything currently on the market. This investment has resulted in improved technologies; translation to the civilian population, however, is fraught with challenges.

Amputees, for example, are often left with limited insurance coverage for prosthetic arms and legs. Children are told they can only have one leg per lifetime or deductibles are so high that families must mortgage their homes to buy an arm or a leg. This is not the case for stents, hip replacements, or pacemakers. Procuring coverage for wheelchairs is similarly fraught with difficulty.

We at the Amputee Coalition of America are fighting for fair insur-

"We live in remarkable times. New technologies and strategies are turning the once unimaginable into reality."



President & CEO, Amputee Coalition of America

ance coverage for amputees. We also develop national peer support programs, operate resiliency programs, and manage the National Limb Loss Information Center (for more information, visit www.amputee-coalition.org). In doing so, we continually see the benefits of technology, the self-lessness of caregivers, and the growing need for fair access to mobility devices.

This report highlights advancements in mobility made possible by the ADA and focuses on organizations leading the charge for enabling accessibility for everyone. Whether you're updating vour home to accommodate for a senior or an individual with a disability, looking for accessible travel tips, or seeking ways to get involved, this report is your guide to living without limitations. The incredible stories on the young athletes who overcame vast physical challenges to race competitively and the woman who reclaimed her independence by implementing universal design in her home will be sure to inspire you. We encourage you to join us in our mission to increase access and mobility for all.



#### WE RECOMMEND



Soldier Ride
A Wounded
Warrior Project
event to reinvigorate
injured soldiers.

"These men and

women are true American heroes."

Accessible travel

ow to plan ahead for your trip

New beginings

A case study of a senior who reclaimed her home and idependence.

## MEDIA PLANET

ADVANCEMENTS IN MOBILITY, 1ST EDITION, SEPTEMBER 2010

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Distributed within:

Washington Post, September 2010. This section was created by Mediaplanet and did not involve The Washington Post or its News or Editorial Departments.

## We support advancements in mobility for all











#### NEWS

There's still work ahead to **expand access for individuals with disabilities**. Policy-makers and advocates focus on the workplace, healthcare, and the Internet for next generation accessibility.



# Expanding access for all

July 26, 2010 marked the 20th anniversary of the Americans with Disabilities Act (ADA), which began the conversation of increasing access for people with disabilities, roughly one in five Americans.

The ADA triggered subsequent laws and societal changes that led to an executive order, signed by President Obama this July, to increase federal employment of people with disabilities.

Obama also pushed hard for healthcare reform that removed pre-existing conditions as barriers to obtaining insurance coverage. "That was huge," says Barbara Otto, president of Health & Disability Advocates. Carol Glazer, CEO of the National Organization on Disabilities (NOD), sees the country at a "tipping point," where disability becomes of greater concern to everyone, due to increased awareness over the past few decades and an aging population who begin to struggle with their mobility as well.

Tele-commuting, for example, enables employees to work at home, which is a boon for everyone from senior employees to

working parents to individuals with mobility challenges; it avoids logistical challenges of actual commuting. Other innovations in technology have played a major role in this space as well. Accessibility is becoming a reality for all through voice-recognition and screen reading technology that assist users who are blind with navigating the Internet. Text-to-speech applications further enable communications for individuals with disabilities.

#### Accessibilty gaps persist

Josie Byzek, managing editor of New Mobility magazine for wheelchair users, is buoyed by the Department of Justice's tougher stance on enforcing ADA regulations on public buildings and transit. But other accessibility gaps will be harder to close. For example, 16.4 percent of individuals with disabilities were unemployed, based on findings of the U.S. Bureau of Labor Statistics in July. However, NOD cites that this does not reflect true employment levels of Americans with disabilities and estimates that only 21 percent are actually employed.

A new Harris Interactive poll of 400 corporate executives found that companies are not recruit-

ing enough applicants who have disabilities. NOD recently initiated diversity hiring programs for retailers Walmart, Sam's Club, and Lowe's to improve in this area. Eric Lipp of the nonprofit Open Doors believes all companies would benefit from having a "designated access coordinator," who could reach out to employees with disabilities and customers.

Health & Disability Advocates' marketing campaign across 38 states, "Think Beyond the Label," urges recognition of people's abilities beyond their shortcomings. In their ads, they humorously poke fun at the familiar co-worker who is a rhythm-impaired dancer or pattern deficient in the wardrobe department

But shifts in perception, asserts Otto, must be matched by greater access to long-term medical and lifestyle support. Proper healthcare coverage for medical equipment and prosthetics ultimately supports wellness, increases mobility, and enables people with disabilities to become employed, tax-paying citizens. "Without these, a person with a chronic disability can't live independently."

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#### **QUESTION & ANSWER**

#### Since the passing of the Americans with Disabilities Act, what still needs to happen to enable mobility for all?

Mobility for all is the ultimate goal, but we are far from it today. The ADA was a significant step that holds great potential but ignores the problems people who need wheelchairs have in getting appropriate equipment. Curb cut-outs and building ramps are great, but if people don't have the correct wheelchair to be mobile in their home and community these benefits are useless.



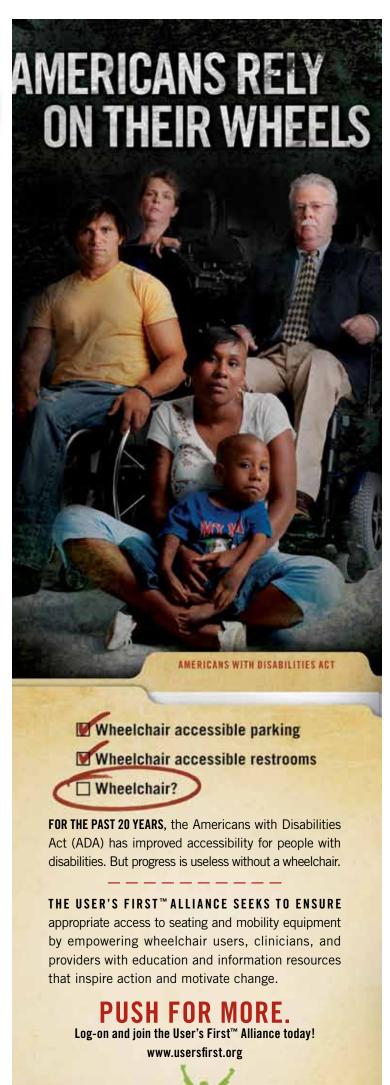
Ann Eubank Executive Director, Users First Alliance

Americans struggle for access to mobility equipment. Current insurance programs typically disregard an individual's essential right for proper mobility equipment to engage in everyday activities. For example, the Medicare program only recognizes mobility needs within the confines of a home. In addition, other programs limit coverage to specific

medical diagnoses and do not recognize a person's fundamental need to carry out basic daily activities.

It is a basic American right for individuals to fully participate within their communities. Unfortunately, significant barriers exist denying this basic right to people who require a wheelchair.

To correct this inequity, policy changes within federal, state and private insurance programs are critical. People who require wheelchairs are entitled to full access and all Americans need to support efforts to make this happen.



#### NEWS

Growing older in one's own home enables **independence** and a **higher quality of life** than being in a nursing home or an assisted living facility.

# Universal design: The practical choice

"Aging in place isn't just an 'old and frail' issue," says Amy Levner, AARP's manager of housing and mobility options.

Universal design, the principle that buildings and living environments are usable and effective for everyone, not just people with disabilities, can be both functional and sleek in appearance. "When you do universal design right, it's invisible," says Mary Jo Peterson, a Brookfield, Connecticut-based kitchen and bath designer.

These solutions can be implemented incrementally by home owners over time. For example, it is relatively inexpensive to add lighting, convert a downstairs family room to an office or bedroom,

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replace doorknobs with levers that are easier to turn, reduce trip hazards such as loose rugs, and install grab bars that blend in to look like towel racks.

Adding a stairlift and creating a walk-in shower or bathtub are ideal solutions to age gracefully in place and help to prevent falls. Furthermore, remodelers and builders are increasingly working with specialists who understand the human form and function, says environmental psychologist Richard Olsen, Ph.D. In this way, the effectiveness of the renovations can be measured and modified accordingly to best meet individual needs.

Many believe that updating their home could break the bank. However, Andie Day, a Certified Aging-

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In-Place Specialist, explains that since the average life expectancy is increasing, upgrading a house to age in place is worth the investment, given that assisted living can cost anywhere from \$7,000 to \$15,000 per month. For younger

families, the effort and expense can make their homes safer for kids as well as more marketable down the road.

However, home owners should start saving early for such renovations to best prepare for aging in place. Experts recommend that people should be thinking about the financial and lifestyle implications of growing older in their homes when they are young, healthy, and still working. To accommodate older home owners, the National Council on Aging (NCOA) is promoting programs that help its members take advantage of reverse mortgages and understand which benefits they are eligible for. Wendy Zenker, vice president at NCOA, says that through this program, 2.5 million Americans have gained access to \$8.8 billion in benefits.

Says Levner, "The good news is that there's a lot that people can do right now."

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## Travel tips for people with mobility challenges

Question: How should travelers with mobility challenges find accessible options?

Answer: Plan ahead and clarify ability level in advance.

Travel can be stressful for anyone, but it is particularly frustrating for individuals with disabilities.

"Lots of people [with disabilities] say, 'It's easier to stay home,' but there are plenty of options," says Jani Nayar, executive coordinator for the Society for Accessible Travel & Hospitality (SATH), which offers a wealth of information to travelers with special

When selecting accommodations, Nayar suggests Microtel Inn & Suites, which provides bigger bathrooms and more accessible rooms. Microtel specially trains its staff about helping guests with disabilities as well.

It's easier than ever before to rent scooters to avoid the hassles of traveling with one's own equipment. "Nowadays scooters are much more appealing and sleek," says Gerald Adams, manager of online resources

"Tell (the booking agent) ahead of time what you're able to do and not able to do, so they can provide the right service for you."

**Jani Nayar** Executive Coordinator, Society for Accessible Travel

for Scootaround, Inc., a national company that rents scooters and power wheelchairs to travelers.

Making local trips are easier as well. More vans have ramps, some of which allow a person in a wheel chair to sit in the front seat. Manual wheelchairs are now easier to maneuver due to geared wheels allowing the user to explore uneven terrain.

#### Plan in advance

A travel agent who is experienced in serving people with disabilities is a great asset. They can help find the best accommodations to match the person's ability level, for example, beds that are ADA-height and wide bathroom doorways for individuals in wheelchairs.

When you make a reservation, call the hotel directly. "Don't just say you're in a wheelchair," says Nayar. "Tell (the booking agent) ahead of time what you're able to do and not able to do, so they can provide right service for you.'

Provide at least 48-hour advance notice prior to boarding a plane, train, or bus, so they can better assist you. Typically, public transportation options offer a disability travel assistance line to call directly. To rent a car with hand controls or other accessibility features, book well in advance to ensure availability.

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#### GJ QUESTION & ANSWER

#### How has Amtrak partnered with disability advocacy groups?

Disability advocacy groups have advised Amtrak regarding training for our employees, train car modifications, and ensuring ADA compliance at the stations we serve. We sponsored events by the American Association of People with Disabilities and the National Association of the Deaf and publicized Amtrak's discount for passengers with disabilities and their companions in a National Council of Independent Living's publication.

#### What is the Great American Station Project?

The Great American Stations Project educates communities on the benefits of renovating their train stations, provides station planning guidelines including complying with ADA requirements, and offers tools to assist them in their redevelopment effort. It also provides



Amtrak President and CEO

detailed information on station services and ownership. potential funding sources for station rehabilitation as well as Amtrak points of contact. (www.GreatAmericanStations.

#### Why are accessible stations critical for travelers with disabilities?

It's important that trains are accessible, but if someone can't get to the train due to barriers at the station, then we haven't fulfilled our mission as America's railroad. We value all of our passengers and strive to make all aspects of the trip more acces-







## INSPIRATION



## Turning challenges into opportunities

■ Question: How can children with mobility challenges build confidence and hit their stride? ■ Answer: The Challenged Athletes Foundation enables them to be competitive athletes.

Brendan Driscoll was born with a tibia and a fibula that did not develop; his lower left leg was amputated before he started kindergarten. While he could use a prosthetic leg to walk, his heart was set on running.

A few years ago, The Challenged Athletes Foundation (CAF), a San Diego-based nonprofit, gave him a running leg. Now 12, Brendan is an accomplished athlete, having participated in 14 races in 19 states.

"Before I met The Challenged Athletes Foundation, I thought I couldn't run as fast as kids at school, but now I'm faster than most of them," says the middle school student from Essex, Mass.

CAF's mission is to provide grants,

support, and training to enable individuals with physical challenges to live active lives.

"The grant program funds prosthetics, hand cycles, basketball chairs—any equipment or coaching to get to the next level," says Lauren Hinton, director of marketing for CAF, which started in 1994 and has given out 812 grants this year totaling over \$1.3 million.

"Brendan is a great example of how sports can help you rise above," says Hinton. "He's doing more than most able-bodied kids."

Ginger Driscoll, Brendan's mother, says CAF changed her son and the family's life.

"The Challenged Athletes Foundation shows us that you can do things you didn't think you could do," she says.

#### **Pricey prosthetics**

Without CAF, Brendan and his family couldn't afford a running leg,





which he outgrows about every six months.

Hinton says prices for running legs range from \$12,000 to \$120,000.

Last year, Brendan joined the Amputee Coalition of America as they went to Capitol Hill to lobby for the Prosthetic & Customized Orthotic Parity Act, a bill requiring insurance companies to pay for prosthetics and devices.

"Insurance companies don't cover running legs and most prosthetics," he says. "I went to talk about how you need running legs to do everyday activities."

Brendan has raised over \$20,000 for CAF's "Race for a Reason" campaign to support challenged athletes worldwide.

#### **Breaking barriers**

Another challenged athlete, Kevin Messner, 10, of Phoenix had his right leg amputated above the knee when he was four due to a congenital birth defect. He's been running races for the past three years after receiving a running leg from CAF.

"Kevin is very shy and sport is helping him break down barriers," says Hinton.

Kyle Messner, Kevin's mother, says, "CAF has taken my son where I hoped he'd go. I think someday he'll be running in the Paralympics. He likes to run, to win, and to beat his times."

Kevin says his new leg helped him shave 15 seconds off his 200 meter time. "I get better at running every year," he says. "It feels good."

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NEWS

#### **Wounded Warrior Project**

One night while watching the evening news, a group of veterans were moved by the difficult stories of the first wounded service members returning home from Afghanistan and Iraq. They realized that something needed to be done for these brave individuals beyond the brass bands and ticker tape parades.

Thus began the Wounded Warrior Project (WWP), an organization that honors and empowers severely injured soldiers. By raising awareness and enlisting public support for the needs of wounded warriors, WWP unites these service members and provides unique programs and services to meet their needs. "These men and women are true American heroes," said Steve Nardizzi, executive director.

One such program is Soldier Ride, which provides adaptive cycling events across the country for wounded warriors to restore their physical and emotional well-being. All participants with a disability or amputation are provided the adaptive equipment customized to their individual needs.

To get involved and learn more, visit woundedwarriorproject.org.



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#### INSPIRATION





When the **doctors recommended** that Sally stay in the nursing home full-time, she was completely distraught.

# Sally's home renovations dramatically changed her life

She felt angry to have lost control over her own living arrangements and was adamant about returning to the home that her deceased husband had built for her and their family over fifty years ago.

After much deliberation, the family agreed that if Sally were to return home, it would have to be redesigned to make it safe and accommodating for her needs. I incorporated aging-in-place elements into her home, such as accessible entryways to the bath and bedrooms which she could enter with her walker, hands-free faucets to reduce the risk of flooding, an auto-turn off stove to replace a

dangerous gas range, as well as cabinets and appliances placed at the right height to reduce the need for bending and straining. Since falls are the number one reason for death and injury in the home, I implemented LED nightlights in the hallways to create safe passage in the dark. A glass front refrigerator was installed to offer a visual cue to caretakers to replenish groceries and to Sally a reminder to eat.

#### With time came improvement

When Sally returned home after thirteen weeks, she had become so institutionalized and dependent on others from the nursing home that it seemed unlikely she could ever live without a full-time



Andie Day Certified Aging-in-Place Specialist

care provider. Sally suffered from early-stage Alzheimer's disease, relied on a walker, had lost significant weight, and had difficulty with daily activities such as turning on the single-button coffee maker.

Over time, however, Sally improved. She regained weight and muscle tone and became fully able to walk again. After one month, she insisted that she no longer needed a caretaker. So, we

developed a support system complete with visiting nurses, Meals on Wheels, family members to take care of grocery shopping, and an automated medication dispenser which makes her laugh each time it calls out to her to take her pills. As the weeks progressed, she was proud to have visitors compliment her on her beautiful home.

Two and a half years have passed since the renovation, and Sally is still living independently and healthfully in her home. Her family members have "peace of mind" knowing that her home continues to provide a safe haven.

#### ANDIE DAY

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#### TIPS

# Remain independent and update your home

- #1 cause of injury and fatality in the home and happen to more than one third of adults 65 and older each year in the U.S.
- **Create well-lit** entry and stairways and eliminate loose rugs. Install handrails on both sides of the stairs and put in grab bars in bathrooms.

#### Accessible appliances

create a safer home. Handsfree faucets prevent accidental flooding, auto turn-off stoves prevent fires, and glass front refrigerators help remind seniors to eat and family members to replenish food.

- Avoid slips in bathrooms by creating walk-in showers and tubs. Shower seats and hand held shower heads are ideal for wheelchair users or seniors who feel more comfortable sitting rather than standing.
- Facilitate mobility by creating wide 36" entry at doorways, adding a stairlift, and replacing circular doorknobs with lever handles which are easier to turn.
- **Easy-to-reach cabinets** that are ADA-height help to avoid bending and straining.
- Select colors that distinguish surfaces, such as the floor from the walls, the edge of countertops, and doorways from walls, to assist individuals with vision impairment.



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