

Inclusive Tourism and AT: And Away We Go!



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In the 1950s comedian and TV variety show host Jackie Gleason opened his prime time Saturday night show by hoisting a coffee cup filled with a mysterious liquid. Glancing toward his studio orchestra, he'd say, "A little traveling music, please." Then, lurching toward the camera, The Great One would bellow, "And awaaaaaaaaaaaay we go!"

For families of children with disabilities going away for a summer trip is easier said than done. There may or may not always be traveling music involved, but there is hard planning and thorough preparation. Fortunately, families engaged in travel planning are not doing so in an information vacuum. Thanks to pioneers such as this month's interviewee Dr. Scott Rains, inclusive tourism is a field of interest that is fast emerging from the shadows into the daylight of the information age.

As defined by Dr. Rains, who invented the term, inclusive tourism is "the comprehensive application of Universal Design by the travel and hospitality industry at all stages of product lifecycle." A related term, inclusive destination development, "similarly starts with Universal Design in looking at the creation, management and marketing of tourism destinations, Dr. Rains notes.

A travel activist and blogger, Dr. Rains produces The Rolling Rains Report (<http://www.rollingrains.com/>) through which he distributes news items and reflections on the tourism industry from the perspective of a veteran traveler with a disability.

Today, as families of children with disabilities who use assistive technology venture forth during vacation season, Rains strongly recommends a structured and thorough planning effort in order to minimize inconvenience and difficulty while maximizing the chances for relaxation, recreation and pleasurable enlightenment.

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“For anyone with a disability and for families of children with disabilities all travel is adventure travel,” Rains points out. The trick for inclusive tourists, though, “is to do everything possible to ensure that the adventure is the right kind of adventure, a positive experience, not a frustrating and negative one.”

This issue examines the concept of inclusive tourism and its impact on families of children with disabilities.

Dr. Scott Rains Speaks

An enthusiastic hiker, camper and skier in his youth, Scott Rains, who grew up in the Pacific Northwest, entered the world of disability very suddenly just before his 18th birthday and less than a week after realizing his greatest triumph to that point: certification as a ski instructor. He awoke after spinal surgery to remove a cancerous tumor paralyzed from the waist down.

Although devastated, the teenager soon found an upside to his disability. “My paralysis occurred at the same time that the disability rights movement and the civil rights movement were going strong. Thanks to my paralysis I was invited into a community of like-minded individuals involved in social change around disabilities.”

Dr. Rains had his first experience with the vagaries of AT use during his first post-paralysis road trip. “My friends and I were headed to a Shakespeare festival in Atherton, Oregon. A car pulled up next to us. The driver said he’d seen a wheelchair in the road about a mile behind us. Uh-oh. We stopped the car and checked. Sure enough, the chair that had been strapped on the top of the car was gone. We found it in the road, exactly where the other driver said he’d seen it. Thankfully, it was undamaged.”

During his college years Dr. Rains founded the first disabled students commission at the University of Washington. “I learned that I do not have the stamina and the hard shell that’s required for the constant political battles involved with being a lobbyist or a legislator.”

Since age 17, he says, “My willingness to emphasize my disability has fluctuated as has my identity as a member of the disability community. Thus, my professional career has centered on non-profits and higher education with the purpose of better serving the under-served. After I’ve been in a job for several years I will include an element connected to disability.”

The career turning point for him occurred when he and his

wife “were doing what we like to do most, driving around northern California and having one of those car conversations that lasts three or four days. One of the conversation threads was, What is realistic for us to do to keep us passionately involved and yet will produce an income stream as we age? For me that meant turning to writing, a task I can perform by dictating to the computer, and travel. I had put off travel early in my life to do other things but it had been of interest to me since high school, when I was an exchange student in two countries.”

Dr. Rains realized because of the unique exposure that he has to disability rights history in the US, including some of the personalities involved -- Seattle was the first locale to develop an accessible transit system, for example -- that U.S. disability history was going to repeat itself worldwide. In such a scenario, he remembers, “I was convinced I could be most helpful to the disabilities community by being a living contact with that piece of history. I could help local disability communities around the world. In the process I could fulfill my desire to travel and to write and my natural gravitation to teaching.”

The result, he says, was his blog, The Rolling Rains Report. At first, he points out, “I kept myself under the radar by only doing select articles and discrete events like the Adaptive Environments conference as well as the international accessible tourism conferences. I continued to remain under the radar until I rolled out my strategy, which focused on contacting the key points in business, academia and government, thereby making first-hand strategic contacts around the world.”

In addition to his blog and advocacy work, Dr. Rains is an executive producer for [with]tv (<http://www.with-tv.com/>) a company developing an inclusive, mainstream television channel to serve as a media presence for people with disabilities. He is also associated with the company’s non-profit arm, PWDBC (People with Disabilities Broadcast Corporation) where he develops broadcast training methods for individuals with disabilities. He is affiliated with the Inter-American Institute on Disability and Inclusive Development, which partners with the cruise industry and deep-water cruise ports along the Atlantic coast of South America to improve accessible travel options for seniors and those with lifelong disabilities, including children.

Dr. Rains earned a B.A. in linguistics from the University of Washington, an M.A. in pastoral ministry from Seattle University and a D.Min. in pastoral ministry from the Graduate Theological Foundation, South Bend, Indiana.

Supporting our interview with Dr. Rains are resources that provide information on inclusive tourism and accessible travel. We also feature members of our Knowledge Network. The members spotlighted this month focus on inclusive tourism and advocacy on behalf of travelers with disabilities. We invite you to contact these members for further information. Please share this newsletter with other organizations, families and professionals who may benefit from it. We invite you to visit us at <http://www.fctd.info>. We welcome feedback, new members and all who contribute to our growing knowledge base.

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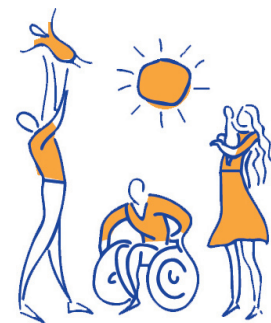
Here at FCTD we always welcome your suggestions for newsletter and discussion topics.

If there is something you would like to see discussed, please contact us at fctd@aed.org

Principles of Universal Design

1. **Equitable Use:** The design does not disadvantage or stigmatize any group of users.
2. **Flexibility in Use:** The design accommodates a wide range of individual preferences and abilities.
3. **Simple, Intuitive Use:** Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
4. **Perceptible Information:** The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
5. **Tolerance for Error:** The design minimizes hazards and the adverse consequences of accidental or unintended actions.
6. **Low Physical Effort:** The design can be used efficiently and comfortably, and with a minimum of fatigue.
7. **Size and Space for Approach & Use:** Appropriate size and space is provided for approach, reach, manipulation, and use, regardless of the user's body size, posture, or mobility.

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Inclusive Travel & AT: All Travel Is Adventure Travel

An Interview with Dr. Scott Rains, Inclusive Tourism Blogger and Disability Rights Advocate

“All travel is adventure travel,” declares Dr. Scott Rains, inclusive tourism trail blazer. “The trick for inclusive tourists is to do everything possible to ensure that the adventure is the right kind of adventure, a positive experience, not a frustrating and negative one. A sense of lightheartedness contributes to the spirit of adventure and can attract help from strangers when help is needed most and makes the trip a whole lot more fun.”



This approach, he insists, is especially effective at helping families of children with disabilities who use assistive technology cope with the unique challenges they face when traveling, Dr. Rains asserts.

The Six Knows of Travel Planning

Careful planning, he emphasizes to parents and others, is the key to creating a positive travel adventure. “Travel can be a time of self transformation. Parents and children with disabilities can grow in confidence and self-esteem while gathering memories that will last a lifetime.” One way to help ensure that result, he says, is adherence to his rules for inclusive tourism, **The Six Knows of Preparing to Travel:**

- 1) **Know yourself** – “Socrates said, ‘The unexamined life is not worth living.’ Take it from me; it’s not worth carting along on the road with you either.” Parents should pare down to the non-negotiables. Arrange a realistic budget based on your means and travel aspirations. Review the physical health of all family members traveling. Evaluate travelers’ physical strength, stamina, immune systems, chronic pain issues and medication supply. Evaluate travelers’ mental health and emotional state and emotional resilience.
- 2) **Know Your Equipment** – Parents should take the responsibility to know their child’s equipment and their own. Create a repair toolkit and include it in the carry-on luggage. Prepare an instruction sheet, with illustrations, for assembling and disassembling AT. Arrange a pre-departure equipment check-up. Bring replacements for items that often fail. Make a list of equipment vendors at each travel destination. Know how to report equipment failures to a vendor and manufacturer. Troubleshoot all equipment prior to departure. Prepare instructions for baggage han-

- dling and equipment stowing. Memorize the accessibility features of the planes on which you have reservations.
- 3) **Know your safety net** – “Traveling with a disability can be a test of skill; expect the unexpected.” Game plan around the worst potential areas of mishap. Parents should leave a copy of their itinerary with friends. Double check contact information for friends you expect to encounter at each destination. Review the family’s insurance coverage.
- 4) **Know your rights and responsibilities** – “Laws, policies, business practices and cultural norms change from region to region and country to country. Keeping track of the specifics merits an advanced degree in traveling with a disability. Be as knowledgeable as possible.” Parents should be aware of the point in a trip when the Americans with Disabilities Act jurisdiction ends and the Air Carriers Access Act (ACAA) begins. Know what accessibility features are required by law in airplanes with more than 30 seats. Are parents capable of advocating for their child with a Canadian or European air carrier?
- 5) **Know your travel companions** – Family members should know what to expect from each other during the duress and fun of travel.
- 6) **Know your destination** – “Destination research is the least overlooked of the Six Knows. Holiday spots can be very effective in communicating their image and color. The danger lies in being lulled into assuming that the specific accessibility information that parents need is easily available.”

“Do the Research; Assume Nothing”

Parents, says Dr. Rains, should make sure that their child is equipped with the correct converters and plugs, plus step-down transformers and other critical accessories.

Parents should contact the hotels or the family that they will be staying with to learn about the environment in which they will be living at each destination. “You could be in a place with a hotel that has both kinds of electricity, static and current, coming into the rooms. I’ve been in hotels where that is the case. Last week, for example, I was up in Alaska. Although I don’t require any life support-type AT I read that the cruise ship I was on turns off the diesel engine when it anchors and that the supplemental electricity is turned off at night. I was thinking about this cruise for my father. I asked the owner of the ship, ‘What happens if a sleep machine is being used?’ He replied, ‘We have battery back-ups.’”

For parents, he adds, the most effective strategies involve knowing precisely what will be needed to support a child’s assistive device. He recommends that parents write out their AT support requirements and send them ahead to their destination. “Every point of contact during the planning process should be carefully addressed, including boarding the plane,

booking the hotel, asking airline or hotel representatives if they are making a written note of the information being provided.” Dr. Rains cautions, “Never assume that the individual with whom you’re communicating has actually taken down the information.”

Dr. Rains believes that each point of contact in the planning process is an opportunity for parents to educate others about their child’s disability. For example, he strongly recommends that parents contact the hotel concierge at each stop on their itinerary to make certain the hotel knows what equipment is being brought. “Ask the hotel to do some research about how to locate replacement sources for things like batteries.”



The reason for this recommendation, he states, “is not [simply] because parents may actually have a need for items like batteries. The real reason for my recommendation is that parents need to place the research responsibility on the shoulders of a concierge or travel agent. This provides these travel professionals with the opportunity to dig into the research themselves.”

In taking this approach “parents are teaching these travel professionals who then become better at their jobs because they are being provided with detailed information accompanied by a sense of urgency, plus clarity and specificity – and at the same time parents are protecting themselves.”

Take the Multi-Modal Approach: Specificity Is King

When communicating information to travel professionals about a child’s equipment requirements, the multi-modal, written/spoken approach is best, Dr. Rains emphasizes. According to Dr. Rains, “Seasoned travelers with disabilities can predict where the important points of contact will be and can therefore educate travel employees before the fact.”

A recurring problem, he says, is care of electric wheelchairs when they are being loaded on an airplane. His advice to parents: “Write up the procedure for breaking down a child’s wheelchair and include clear instructions about what must never be done during that process, plus answers to frequently asked questions, such as, ‘Is this a gel battery? Does it contain acid?’ Write the directions and comments in English on one side of the piece of paper and in Spanish, or another appropriate language, on the other side.”

The instruction sheet, he adds, should be laminated, hole-punched, attached to a bungee cord and attached to the chair “so that even if you are not present the individual who is loading baggage will be educated.”

In other words, Dr. Rains advises, parents should always have a set of written answers to the questions they will likely be asked about their child’s AT. He urges parents to manage the process by making certain the document gets into the hands of a hotel manager or cruise ship director. Reiterate those instructions and information in the conversations, he suggests. Parents, he says, “will then have the satisfaction and the relief of knowing that their spoken words will be documented on a paper that is circulating through the organization or institution.”

“Disability Imposes a Discipline”

“Disability imposes a discipline,” Dr. Rains asserts. “We all chafe at discipline, but we can grow from it if we use it skillfully. Any travel with another person requires that what ‘I’ want to do



will not always be what we as a group actually do. There should be a respect for the unexpected when traveling.”

There is an advantage from having multiple players on a family travel team. “Parents can do the good cop, bad cop routine to get what they need from travel professionals.” Employing this strategy, he notes, “can produce the same effect – called “mobbing” by birdwatchers – generated when flocks of birds descend on a food source and hop around to distract potential predators.

However, he warns, “the flip side of mobbing is that if a story is not tight inside a family, conflicting instructions and information may inadvertently be imparted to those who are trying to help or with whom parents are trying to communicate.” Rehearsing those interactions can be very helpful, he advises.

“Help the people on your family travel team understand what needs to be communicated to a specific person at a particular time. If you don’t feel that the person who took the lead in communication did it effectively in terms of content you can supplement the content while being careful never to contradict instruction. If that person was worn out or short-tempered you can mollify by asking him/her to say the same thing in another way or introduce humor, which is a way to engage and motivate the person who is providing services and to whom your need is being communicated.”

Putting the Child Forward

A family travel team approach is also helpful when team members become tired or short-tempered or may not be proficient at some aspects of travel, Dr. Rains notes. "Maybe a person provides the brawn and not the silver tongue. If that is the case you sequester that team member until he/she is needed."



What can be satisfying to parents is putting their child forward, even if the child has communication disabilities, Dr. Rains says. "Have the child use his/her talking table or voice communicator and take responsibility in a controlled environment where the child is going to succeed and also educate the service provider."

A few years ago Dr. Rains implemented this strategy when he was employed by a community comprised of individuals with and without disabilities living together in upstate New York. "One of the traditions in this community is that everyone gets to 'take a vacation', those with disabilities and those without." In a parental role he traveled with community members as someone with a physical disability supervising other members with developmental disabilities.

"In one case I was living in Syracuse, New York with the community and had traveled home to visit my family in Seattle. Accompanied by other community members I was returning my car East by driving cross-country. We crossed the Canadian border at the Peace Arches in North Dakota. It was late at night. Given the nature of our group we didn't expect much scrutiny at the border. We were so wrong."

The group of disabled people trying to cross the border raised much suspicion on the part of the Canadian border patrol. "In short, they were giving us a hard time. The border guards could see that the guys in our back seat had Down syndrome, which made them suspicious of us." The group was ordered out of the car.

"I got out with the wheelchair. I'm sure the border guards thought they had captured some sort of 'coyotes' (illegal immigrants). They were tough on me. Finally, I was the one who needed to be sequestered and not do the communicating. I told the guards, 'You're talking about these individuals as if they're invisible. I'm not going to answer questions for them. They're perfectly capable of giving you answers. But you're going to have to figure out how to get those answers.'"

A member of his group was a "jokester" with minimal intel-

lectual capacity, "but he held his own when the guards realized that they were going to have to deal with this situation themselves. Another fellow traveler had non-functioning vocal cords. He typed things out on what appeared to be an old adding machine with a roll of tape. He was slow, slow, slow in his writing. He'd pause between every letter that he typed. The guards asked a question, like 'How much money do you have?' He would type out his response, digit by digit, print it out and hand it to them slowly. I'm sure that that was a life-changing experience for those border guards!"

Parents: Share Your Story

In order to minimize challenges and maximize the chances of travel success, Dr. Rains urges parents of kids with disabilities to "share their story" while the trip is in the planning stage by announcing their travel intentions via participation in parent-to-parent blogs and bulletin boards like Cruise Critic <http://www.cruisecritic.com/>, a popular site for those who are planning cruises.

"Post on multiple bulletin boards," he advises. When posting, parents should state their destination and ask for opinions of that destination. "I urge families of children with disabilities that have traveled to document, provide kudos or blacklist travel agents, destinations and accommodations." Again, specificity of information is key, he cautions.

"Go to <http://www.tripadvisor.com/>. Post photos of accessible bathrooms and public spaces that show accessibility. Write reviews. Create a new group for travelers with disabilities to share reviews regarding accommodations."

"I have been working with two other new travel sites that have pleasantly surprised me with their awareness of the needs of travelers with disabilities: VibeAgent (<http://www.vibeagent.com/>) and Trip Wolf (<http://www.tripwolf.com/>). I was able to work with both before the sites went live and helped them identify issues related to web site accessibility and providing the right sorts of destination data for parents traveling with a child who has a disability. At either site you can find me and the reviews I have done under the screen name 'Rolling Rains.' "

When parents have experienced travel with their child, when they have negotiated their way through a trip, "leave a trail for those who follow. Hotel owners may or may not appreciate your efforts although my experience is that most do appreciate these evaluations."

Parents should consider creating a caucus within any kind of organization in which they are involved as a parent of a child with disabilities. "Create that caucus specifically around travel and travel issues," he urges.

Children Traveling with Their Peers

Occasionally older children with disabilities travel with their friends but not their parents. In such situations Dr. Rains offers the following advice:

“A lot of the problem-solving involves pre-planning that inculcates resiliency and handiness with problem-solving. At a certain point in your teenage years it is your job to break away from everything that is constraining you.

On the one hand it is very important for families to understand that kids, even those with disabilities, are going to put themselves in risky situations. Planning for a child’s trip with his or her peers has more to do with parenting than with trip planning: Let the child mess with and adapt [equipment and care routines] in order to arrive at the right AT solution, whether that’s durable medical equipment or ways that they are being lifted, let them own that.”

He continues, “If children are mechanically minded let them tear the equipment apart and put it back together, because travelers are sometimes their only resource. That’s one practical approach that is related to travel but focused on parenting. Get to know your kid’s companions. Parents who are unable to talk their child out of being friends with someone of whom they don’t approve can provide their child with strategies for dealing with peer pressure. They can also give the child their heartfelt insights about his/her friends’ potential strengths and weaknesses as traveling companions, i.e. who’s not a good driver, who will likely not be careful with the child’s AT.”

In Dr. Rains’ case, when his wheelchair fell from his traveling companion’s car [on a road trip during high school], “our driver was super responsible. He went on to spend his professional life as a counselor for at-risk youth in Alaska. But he was totally shocked and embarrassed when he learned that the wheelchair had fallen out of the car. His embarrassment resulted in an incredible bonding experience between us because somehow the darned thing didn’t break when it collided with the pavement!”

“A Worldwide Commonality”

Much of Dr. Rains’ advice to parents and other travelers with disabilities is dispensed on his blog, The Rolling Rains Report, which he has provided since 2004. “I write every day. I write articles or thought-starters. I relay news articles or press releases. I’m trying to reach readers with disabilities who travel, or the travel industry itself, including individuals responsible for making decisions or providing services to those who travel.”



The blog’s strategic purpose, he explains, is to create awareness of a centralized resource of information. “It’s a tool to attract individuals to me who then provide me with further information that I can use in articles or presentations.” The news items that attract his attention, including new products or recent reviews or articles or travelogues, are often contributed by fellow travelers with disabilities or companions of travelers with disabilities.

Responses and contributions to The Rolling Rains Report, he notes, are numerous, knowledgeable and spirited. “I’m finding a worldwide commonality in terms of the issues I write about. That’s encouraging to me because it indicates a high baseline of understanding and awareness about disabilities.”

In fact, he adds, “I find stronger ideological support for people with disabilities as travelers outside the US, outside the developed world.” The reason, he explains, is that many less developed countries have a greater dependence on tourism dollars for their gross national product. “Tourism dollars become a cultural fertilizer and source of cash inflow that determines, in many cases, what a location will look like in terms of physical infrastructure.”

“Adaptations Are Made for Us”

“As people with disabilities travel self-aware of who they are and with cash to spread around, the physical landscape changes to accommodate them,” Dr. Rains declares. “This accommodation has not been carried out with any degree of sophistication or even systematic thought but thoughtful systemization is nevertheless beginning to appear,” he says.

“I’m finding that even small mom-and-pop hotels, resorts and restaurants have an awareness of my needs as someone in a wheelchair and are delighted to hear whatever advice I want to provide when I stop in.”

According to Dr. Rains, that level of awareness is not as high in Europe and the US. He has a theory as to why that disparity exists. “Speaking as a person with a disability who has been paralyzed as a quadriplegic since 1972, I – we – have worked really hard to articulate and translate into legislation our needs and desires and our political agenda.” That effort, he insists, “has created a backlash, especially in the US, where Americans are so litigious.”

Claims Dr. Rains: “A law becomes a challenge to those who want to circumvent it, an approach that creates a degree of tension for parents traveling with a child with a disability. Where there is a less developed economy and less precedent you see a higher level of resourcefulness.”

In such environments, he adds, “proprietors are interested in serving customers. If the customers are people with disabilities and there are no laws or precedent then we are simply accepted as customers. Adaptations are made for us. Sometimes the adaptations are quite creative. This was surprising to me. Of course this attitude is not universal but it is common among entrepreneurs and the merchant class of less developed countries who have monetary incentive, despite cultural differences with their customers, to adapt to disabilities.”

UN vs US

Dr. Rains points out that there is a significant difference between the United Nations’ Convention of the Rights of Persons with Disabilities (CRPD) and the US approach to participation in cultural life, recreation, leisure and sport, a disparity that impacts inclusive tourism.

A key distinction is due to a difference between definitions of disability, Dr. Rains says. “When the Americans with Disabilities Act was passed in 1990 we had educated the government for more than 30 years about our political consensus as a community of people with disabilities and had communicated that neither a ‘charity’ nor a ‘medical’ approach was acceptable. In the ADA the result was to emphasize the social nature of disability and the social nature of discrimination based on differences in abilities.”

The ADA, he notes, defined disability “as something that interferes with one of more activities of daily living. Historically that was a good definition in its era and is a consensual statement of the disability community’s understanding of what our political agenda was. Most important, the definition served as a rejection of the ‘charity’ and ‘medical’ models of disability as applied to us as citizens or as travelers.”

There is an evolving definition of disability which is rooted in the social description of disability, he says. That definition flows from the International Catalog of Function (ICF) which is affiliated with the World Health Organization. The definition describes disability as an interaction between functionality, ability and environment.

“This definition is much more applicable, flexible and forward-looking. On the one hand there are those individuals in physiometrics who are seeking to determine the ranges of function – including reach, visual and auditory – in human populations and apply those findings to standards of design and/or policy development.” That is what the UN Convention on the Rights of Persons with Disabilities (CRPD) focuses on and that is where we ought to be,” Dr. Rains declares.

“We are working on the ADA Restoration Act, which a year ago was introduced in the Senate and House with bipartisan

support. The legislation is a response to court challenges to the ADA. Incorporating newer definitions, like that in the UN convention, can help realize the potential of the ADA in the US based on newer definitions emerging from the WHO.”

The UN convention, he explains, is a compendium of systematic documents on the rights of people with disabilities and acts as a screen through which individual nations sieve their own standards for people with disabilities and measures them against these articles. CRPD is the gold standard on the rights of people with disabilities and the focus of CRPD is Article 30, which includes leisure sports and tourism.

“The difference at one fundamental level is a difference in definition. In addition, the CRPD establishes a right to cultural participation and to leisure and travel. It’s the first human rights document with that focus. That is very significant and raises the bar for the US.”

“We Are Ambassadors”

US travelers with disabilities, including families of children with disabilities, represent all Americans with disabilities when overseas, Dr. Rains asserts.

In a December editorial he wrote for *New Mobility Magazine*, Dr. Rains emphasized that American travelers with disabilities “are ambassadors for a culture that we refer to as ‘disability culture.’ We surprise people when we visit places that are paternalistic and protective, everything that we have fought against as a disability rights movement. But in fact we are a living example in that location and we ought to be aware of how privileged we are to be present at this cultural turning point every time we as disabled people travel around the world.”

He encourages families of children with disabilities to go about their travel with a pilgrim’s reverence. “It’s like carrying a soap bubble in your hand that’s fragile and precious. Taking that approach keeps travelers with disabilities aware of the unique possibilities being created right in front of your eyes. That in itself represents the biggest challenge: to not be overwhelmed by the very real physical and cultural challenges we face when traveling with a disability or when traveling, as a caretaker, with more than one person who has a disability. That is the central point of everything I do, everything I write.”

Inclusive Tourism and Universal Design

Dr. Rains says that he coined the term inclusive tourism. “I conceived it, defined it and was the first to publish articles about it.”



He was very strategic in his approach, he notes. “Inclusive Tourism is the phrase that I use and am trying to have universally adopted because I want those with whom I communicate to understand that there is a cultural and political agenda behind what I do.”

On a very specific level, he insists, “inclusive tourism means that we are applying the seven principles of Universal Design to travel.” If the concept does not include a design phase, an imagination phase where individuals with disabilities and those with a range of abilities are not included in the creation of the product, space or policy using those principles of Universal Design then it is not Inclusive Tourism or Inclusive Destination Development as I mean it.”

His creation of the term was inspired in the 1970s by the work of architect Ron Mace, founder of the Center for Universal Design at North Carolina State University. Explains Dr. Rains: “Mace’s work has penetrated housing design and aging in place as well as aspects of gerontology in the US.” Therefore, he declares, “I intend Inclusive Tourism to mean the use of Universal Design by the travel and hospitality industry and also the cumulative best practices and the self-generating cycle emanating from that.”

According to Dr. Rains, quoting the definition formulated by Adaptive Environments, Universal Design is a framework for the design of places, things, information, communication and policy to be usable by the widest range of people operating in the widest range of situations without special or separate design. “Most simply, universal design is human-centered design of everything with everyone in mind.”

Universal design, he notes, is also called Inclusive Design, Design-for-All and Lifespan Design. “It is not a design style but an orientation to any design process that starts with a responsibility to the experience of the user. It has a parallel in the green design movement that also offers a framework for design problem solving based on the core value of environmental responsibility.” Universal Design and green design, he adds, “are comfortably two sides of the same coin but at different evolutionary stages. Green design focuses on environmental sustainability, universal design on social sustainability.”

Green design and Universal Design, he remarks, “are the two ascendant hot concepts in architecture and social planning. However, when I talk about Inclusive Tourism I am referring to social inclusion. When I first used the expression ‘inclusive tourism’ I was aware that I would confuse some people in the tourism industry who refer to ‘all-inclusive packages.’ I really mean social inclusion and the social movement supporting that inclusion. I wanted to signal that

meaning to consumers and those inside the travel industry who possessed a political orientation toward cultural inclusion and diversity. That way it would be easier to weave related concepts together in people’s minds.”

A “Revolutionary Program” for the Travel Industry

He advocates “a revolutionary program” in the travel industry to promote inclusive tourism. “I went about this in a very systematic way. I got my strategy from Peter Senge’s reflections on the writing of his book, *The Fifth Discipline: The Art & Practice of the Learning Organization* (Doubleday 1990).”

Senge, Dr. Rains says, “writes about being your own competitor, about being a thought leader in an area, that a thought leader must define his/her terms, phrases and concepts as well as sharing ‘springboard stories’ that analogize and make connections between concepts that will be familiar to the readership of the FCTD Newsletter along with the new configurations that the thought leader is striving to get across.”

Dr. Rains began, he explains, by doing survey studies of individuals who were pioneers in specialized travel – traveling with disabilities – as well as travel agents and tour operators. He distributed talking points to specialized travel writers who focused on travel and disabilities. He scanned all related information on the web and began correspondence with mainstream travel writers and travel agencies, developing a network of individuals who came to share his perspective on specialized travel.

Next he collaborated with entrepreneurial individuals, disabled and non-disabled – to help them set up specialized agencies or what Dr. Rains calls “second generation,” i.e. mainstream businesses involved in tourism that want to tap into the specialized travel market.

He defined Inclusive Tourism in academia as editor of the first issue of an academic journal in the field of Disability Studies to address tourism and disabilities. The article appeared in the journal *Review of Disability Studies* (University of Hawaii 2005).

Dr. Rains maintained a tireless advocacy campaign. “I did as many interviews as I could. I traveled and helped organize international conferences on inclusion in tourism, in Taiwan and Australia.”

Dynamic AT Trends for Inclusive Tourists

According to Dr. Rains, several salient trends are emerging that will benefit travel and tourism for families of kids with disabilities who are AT users.

“Right now I’m traveling with a device called SPOT, a GPS

tracking device. We are seeing the advent of Google maps and low-cost personal GPS satellite tracking devices, whether they have a map or send a signal like SPOT does. You push a button and the message goes out that says 'I'm here and I am safe.' Push another button and the message is, 'I'm here and I am in trouble.'" There are also other devices such as watches that enable parents to track their kids' location, which are useful for safety, for orientation and for navigation.

"There is work being done on ruggedizing luggage as cost-crunched airlines become less and less service oriented. There is an awareness that boomers are traveling. Travelwise, the three main boomer characteristics are: the desire to travel; the economic means to travel; and the time to travel. Boomers, being this huge population bulge, will transform the tourism industry by their numbers and by their character as a generation.

As the generation moves en masse into the travel and leisure age "we are going to acquire disabilities. There is something very significant about this trend from my perspective as someone who self-identifies as disabled and as a long-time participant in the disability rights movement: Those who acquire disability at an older age do not self-identify as disabled."

This trend, he notes, is important for the travel industry and has relevance for families of children with disabilities "because those parents will find common ground with seniors as family members or as fellow travelers. "That common ground comes from a desire for what some of my colleagues in Australia term 'easy travel.'"

A Legacy

Asked to sum up his legacy in a sentence or two, Dr. Rains replies, "I saw a need that had to be met on behalf of travelers with disabilities. Meeting that need has fulfilled my own need to build something that is intellectually challenging, adventurous, sustainable and satisfying as my disability becomes more and more debilitating."



RESOURCES

Articles

Wheelchair Adventure Travel and Kayaking in Glacier Bay, Alaska

By Scott Rains
e-bility.com

The author, creator of the blog The Rolling Rains Report (<http://www.rollingrains.com/>), is a mid-50ish quadriplegic well-known for his online commentaries on his "adventure travel" journeys worldwide. He writes, "Thirteen feet below me the water is the murky grey-green of salt-water laced with glacial silt. My bright red snowboarding pants reflect off the glassy surface but, like a mirror, nothing below the surface is visible. The naturalists onboard tell me that spots like this roil beneath with sea life in a feeding frenzy." The article includes photos of accessible facilities.

<http://www.e-bility.com/articles/access-alaska.php>

Have Wheelchair Will Travel

By Donna Goodacre
e-bility.com

The author writes, "We are a family of four - Donna and Neil (parents), Chelsea (14) and Richie (18). Richie has cerebral palsy which restricts his mobility. He can communicate normally but cannot walk unaided. His chair is a manual one which he can operate, but he usually depended on us during this 'trip of a lifetime.'" Her travelogue describes Richie's trip to Australia, Singapore, Thailand, England and France in detail, an interesting read for families of children with disabilities planning their trips.

<http://www.e-bility.com/articles/wheelchair-travels.php>

Inclusive Tourism: A New Strategic Alliance for the Disability Rights Movement

By Scott Rains
e-bility.com (2007)

Presented by the author at the November 2007 International Conference on Accessible Travel (ICAT), the article describes the three "models" of disability: the charity, medical, and social models. The first two, Rains maintains, "present individuals with disabilities as recipients rather than sources of action. They prevent people with disabilities from political expression and economic participation as adults because both models assume worlds that are too small for real people."

The social model, which Dr. Rains endorses, "claims that the world where people with disabilities "really" belong is the real world, the whole world - like everybody else!

That's a big world." Universal design, he adds, "is what lets us live at home in this world." Dr. Rains calls for an alliance between the disability community, governments and businesses to accelerate the evolution of accessible travel.

<http://www.e-bility.com/articles/inclusive-tourism.php>

Before You Go: Accessible Travel Tips

By Bruce Mumford
e-bility.com (2007)

Australian travel expert Bruce Mumford provides travel tips for travelers with disabilities, their families and traveling companions. The highlights:

- Take plenty of medication
- Choose a good airline and inform the airline's representatives of special needs
- Book ahead
- Don't rely exclusively on "wheelchair friendly" access symbols
- Purchase travel insurance to cover medical emergencies
- Bring a "disabled parking" pass
- Don't be afraid to ask for help

<http://www.e-bility.com/articles/accessible-travel-tips.php>

GUIDES

Wheelchair Travel Guide

Access for Disabled Americans (2007)

This trip planner for wheelchair users provides information on locating accessible hotels and on air travel, ground transportation and cruises. The 160-page guide is published in a spiral binding for convenient lay-flat reading. Cost: \$30.00 USD. Cost is considered a donation. A donation slip accompanies shipment. For more information, contact:

Access for Disabled Americans

3685 Mt. Diablo Blvd. #300

Lafayette, CA 94549

Phone: (925) 284-6444 Fax: (925) 284-6448

Email: psmith@aol.com

http://maxpages.com/disabledaccess/WHEELCHAIR_TRAVEL_GUIDE

Wheelchairs on the Go: Accessible Fun in Florida

This access guide is aimed at Florida visitors and residents who use canes, walkers or wheelchairs or are unable to walk more than a short distance. The 424-page paperback lists wheelchair accessible and barrier-free accommodations, tourist attractions and activities throughout Florida.

<http://www.wheelchairsonthego.com/index.html>

WEBSITES

Access-Able Travel Source

Created in 1995 this site offers information on a variety of topics relevant to travelers with disabilities. Links are provided for the following topics: world destinations, travel professionals, cruise ships, "travel tales," magazines, a featured destination and tips of summer fun.

http://access-able.com/graphical_index.html

Accessible Journeys

Founded in 1985, this organization provides information on vacation planning, group tours, group cruises, individual accessible cruises, licensed travel companions and disability travel resources for slow walkers, wheelchair travelers and their family and friends.

<http://www.disabilitytravel.com/>

Global Access News

GAN is a travel network for individuals with disabilities, providing information on accessible travel options for wheelchair users and others who are mobility-impaired. The site offers an extensive archive of travel reports as well as information on accessible accommodations and trip planning. Travel books and a free E-Zine are also available. <http://www.globalaccessnews.com/>

World on Wheels

Dedicated to wheelchair travel, this site is comprised mainly of first-person trip reports that concentrate on a specific destination's accessibility and attractions.

<http://www.geocities.com/Heartland/6295/info.htm>

Disabled Travelers.com

This site offers a comprehensive listing of businesses worldwide specializing in disability travel, including travel agents, tour operators, adventure travel companies, accessible cruise specialists, accessible van rentals and equipment and access guides.

<http://www.disabledtravelers.com/>

Internet Pubic Library (IPL)

IPL offers articles on accessible travel via links to accessible travel resources.

<http://www.ipl.org/div/subject/browse/ent87.04.00/>

PUBLICATIONS

Ability Magazine

The magazine is published bi-monthly and features articles on a range of disability issues including travel. Cost: \$29.70 USD per year. For more information, contact:

Ability Magazine

1001 W. 17th Street

Costa Mesa, CA 92627
Phone: (949) 854-8700; (949) 548-5966
Email: ability@pacbell.net
<http://www.abilitymagazine.com>

Abilities Magazine

Published by the Canadian Abilities Foundation, this is Canada's foremost cross-disability lifestyle magazine. The publication is available in print, on audio cassette and computer disk. All past issues can be accessed in the Abilities Archive section of the magazine's website. In addition to its subscriber base, the magazine is distributed across Canada to every disability organization, plus corporations, professionals and government officials. Cost: \$14 USD for one year, \$34 USD for two years. For more information, contact:

Abilities Magazine
Canadian Abilities Foundation
#501 - 489 College St.
Toronto ON M6G 1A5
Phone: (416) 923-1885
Fax: (416) 923-9829
Email: able@interlog.com
<http://www.abilities.ca>

Active Living

Formerly Disability Today, this bi-monthly magazine focuses on ways to improve health, fitness and mobility, where to enjoy accessible leisure and what to look for in a new therapeutic, recreational or sporting activity. Cost: \$19.97 USD per year; add \$30 USD to all non-US international subscriptions. For further information, contact:

Active Living
PO Box 237
Grimsby, ON L3M 4G3 Canada
Phone (905) 309-1639 Fax: (905) 309-1640 fax
Email: activelive@aol.com

Emerging Horizons – Accessible Travel News

This quarterly magazine focuses on travel options available to individuals with disabilities. Cost: \$14.95 USD; non-US \$19.95. For further information, contact:

Emerging Horizons - Accessible Travel News
Candy & Charles Creative Concepts
P.O. Box 278
Ripon, CA 95366
Phone: (209) 599-9409 Fax: (209) 599-9482
Email: horizon@emerginghorizon.com
www.EmergingHorizon.com

Hearing Health

A quarterly publication, Hearing Health covers all aspects of the deaf community, including lifestyle and travel. Cost: \$24.00 USD. For additional information, contact:

Hearing Health
PO Drawer V
Ingleside, TX 78362-0500
Phone: (361) 776-7240 Fax: (361) 776-3278

New Mobility

Published by No Limits, this monthly magazine covers a range of disability issues, including articles on travel, sports and recreation. Subscription cost: \$27.95 USD per year. For further information, contact:

New Mobility
P.O. Box 220
Horsham, PA 19044
Phone: (888) 860-0344 (toll free); (215) 675-9133
Fax: (215) 675-9376
Email: Ginal@jvleonard.com
<http://www.newmobility.com/>

Paraplegia News

Published by the Paralyzed Veterans of America this monthly magazine provides information on travel-related subjects as well as on sports and recreation. A monthly column is entitled "Travel Tips." Cost: \$23.00 USD per year. For more information, contact:

Paraplegia News
2111 E. Highland Ave., Ste. 180
Phoenix, AZ 85016
Phone: (888) 888-2201 X19 (toll free); (602) 224-0500
Fax: (602) 224-0507
Email: pvapub@aol.com
www.pn-magazine.com

Special Living

This quarterly magazine covers most disability issues, including travel, in each issue. Cost: \$12.00 USD per year. For additional information, contact:

Special Living
PO Box 1000
Bloomington, IL 61702
(309) 825-8842
Email: gareeb@aol.com
www.SpecialLiving.com

We Magazine

We is a lifestyle publication for all individuals with disabilities. Cost: subscription is free. For further information, contact:

We Magazine
495 Broadway, 6th Floor
New York, NY 10012
Phone: (800) 963-2426 (toll free); (212) 941-9584
Fax: (212) 941-6459
Email: editors@wemagazine.com
<http://www.abilitymagazine.com>

KNOWLEDGE NETWORK MEMBERS

Access Tours

A non-profit organization, Access Tours packages all-accessible tours of the American West, including national parks, for tourists with disabilities, especially slow walkers, scooter and wheelchair users and those who accompany them. The typical tour consists of 8-10 travelers. Access Tours is a service of the Access Institute.



For additional information, contact:

Access Tours
PO Box 1320
Driggs, ID 83422
Phone: (800) 929.4811 (toll free); 208.787.2338
Fax: (208) 787.2332
Contact: Clint Grosse, Director
Email: access@silverstar.com
<http://www.accesstours.org/>

Adaptive Environments (AE)

Founded 29 years ago, AE has been a lead organiza-



tion in the universal design movement, having hosted or co-hosted five international conferences on universal design, as well as student design competitions, smaller regional meetings and publication of web and print materials. AE maintains a collaborative relationship with the International Association for Universal Design in Japan, the Design-for-All Foundation in the European Union and the United Nation's Department of Economic and Social Affairs. AE is currently working with the UN on the implementation of the new Treaty on the Human Rights of Persons with Disabilities that endorses universal design as the basis for design guidelines. For more information about AE, contact:

Adaptive Environments
180-200 Portland Street
Suite 1
Boston, MA 02114
Phone: (617) 695-1225 (Voice/TTY)
Fax: (617) 482-8099
Email: info@AdaptiveEnvironments.org
<http://www.adaptenv.org/index.php?option=Content&Itemid=1>

Deaf Globetrotters Travel

For over forty years, Deaf Globetrotters Travel has been arranging and



creating travel experiences for their clients with hearing impairments. With an expansive knowledge of popular travel destinations, they have designed river and ocean cruises and land tours, available throughout the year. They have certified sign language interpreters to accommodate their travelers on all of their escorted tours.

For more information on Deaf Globetrotters Travel, please contact:

9618 Oregano Circle
Houston, TX 77036
Phone: (800) 646-8157
Contact: Don Hahn, Owner
deafglobtravel@gmail.com
<http://www.deafglobetrotterstravel.com>

National Federation of the Blind Travel and Tourism Division

The NFB Travel and Tourism Division works with local NFB chapters, state affiliates, and the national organization to promote travel for individuals who are blind or have visual impairments. They also work toward encouraging those individuals to pursue careers in the travel and hospitality industry. As a part of the national organization, the Division provides access to all NFB publications. The publications provide a variety of resources on living with visual impairments and blindness, including information on accessible tourism.

For more information, please visit:

<http://www.nfb-travel.net/>

Society for Accessible Travel and Hospitality (SATH)



Founded in 1976, SATH fosters awareness of the needs of travelers with disabilities in the US and overseas. SATH participated in the writing of the regulations for the Americans with Disabilities Act and the Air Carriers Access Act, as well as Resolution 700 and 1700 of the International Air Transport Association. A Code of Conduct toward travelers with disabilities written by SATH was adopted by the World Tourism Orga-

nization in 1991. SATH provides detailed training on how to serve travelers with disabilities, organizes conferences and provides speakers and panels for other industry. SATH has sponsored the World Congress for Travelers with Disabilities and the Mature since 1977 and also sponsors Travelers with Disabilities Awareness Week, created in 1990 by SATH founder Murray Vidockler. Since its inception, SATH has served as a clearinghouse for access information. SATH's travel magazine, Open World, features articles by travelers with disabilities and updates on destinations, cruises, web sites and legislation.

For further information, contact:

Society for Accessible Travel & Hospitality (SATH)
347 Fifth Ave, Suite 605
New York, NY 10016
Phone: (212) 447-7284
Fax: (212) 447-1928
E-mail: sathtravel@aol.com
<http://sath.org/>

Student Air Travel Association (SATA)

SATA is an international association of student travel agencies committed to providing accessible and affordable travel for fulltime students and youth under age 26. SATA agents maintain a distribution network of 2,500 retail outlets worldwide. SATA agents have negotiated partnerships with more than 80 airlines around the globe. For further information, contact:

Student Air Travel Association c/o IAS
Keizersgracht 174-176
1016 DW Amsterdam
The Netherlands
Phone: +31 20 421 28 00
Fax: +31 20 421 28 10
Email: satainfo@istc.org
<http://www.aboutistc.org/sata/index.html>



The Guided Tour, Inc.

This organization offers supervised travel and vacation programs in the United States and overseas for individuals with developmental and physical challenges. It is staffed by professionals who have experience working in the field of mental retardation and developmental disabilities. The travelers they accommodate include individuals, ages 17 and up, with mental retardation, developmental disabilities, Down Syndrome, autism, learning disabilities, Williams Syndrome, Asperger Syndrome, ADD, Prader



Willi, and ADHD. They accept people from all over the country and their guided tours offer both recreational and social opportunities.

For more information on The Guided Tour, Inc., please contact:

7900 Old York Road; Suite 114-B
Elkins Park, PA 19027-2339
Phone: (215) 782-1370
Toll-free: 1-(800) 783-5841
Fax: (215) 635-2637
Gtour400@aol.com
<http://www.guidedtour.com>

Travelin' Talk Network

The Travelin' Talk Network is a global network of individuals



both with and without disabilities. The goal of the network is to share information on accessibility issues and safety while traveling. Individuals living in a particular travel destination are able to share information that will may eliminate barriers in communication or mobility that could potentially arise. They can also serve as an emergency contact in their home town if someone is visiting and may need assistance. This is a members-only network. The benefits of joining include a monthly newsletter, access information, and resources. Members also receive various hotel discounts.

For more information on the Travelin' Talk Network, please contact:
<http://www.travelintalk.net>
traveladmin@travelintalk.net

Project Director: Jacqueline Hess

Newsletter Editor: Thomas H. Allen

Design and Distribution: Ana-Maria Gutierrez

Project Support: Annie Czapp



Family Center
on Technology
and Disability

www.fctd.info

Family Center on Technology and Disability

1825 Connecticut Avenue, NW

Washington, DC 20009

Phone 202-884-8068 Fax (202) 884-8441

fctd@aed.org www.fctd.info