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## **Travel and Tourism Through the Lens of Disability Studies**

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The purpose of this Forum is to establish the topic of travel as a legitimate and illuminating area of inquiry within the broader realm of Disability Studies. My hope is to provide a volume containing works that will be foundational as well as evocative of future lines of research. To that end, this Forum began with a call for papers addressing four topics:

- The history of inclusive travel (travel accommodating those with disabilities)
- The impact of travel on self-identity and disability culture(s)
- The representation of travelers with disabilities in the myth and practice of the travel and hospitality industry
- The place of Universal Design in the sustainability of inclusive travel

### **History**

“Toward a Global History of Inclusive Travel,” by Laurel Van Horn and Jose Isola, is the first published attempt to document the history of inclusive travel. Van Horn, from the USA, and Isola, from Peru, trace this development as one of many topics within the disability rights movement. The authors bring extensive personal knowledge of the emergence of a movement promoting inclusive travel and its maturation process.

Muriel Larrouy examines the development of the disability rights movement in her native France in the article, “Invention of Accessibility: French Urban Public Transportation Accessibility: 1975 to 2004.” She writes as a sociologist

through the lens of Baker’s theory of the moral enterprise. Her study analyzes the campaign for accessible public transit in France and the transformative effect on both disability advocacy groups and the definition of disability.

### **Self and Cultural Identities**

An ethnobotanist, My Lien T. Nguyen plunges into the complex intersections created when a Vietnamese-American, wheelchair-using scientist undertakes field research in Vietnam. Part travelogue – recounting the logistical realities of travel and suggesting practical solutions - and part orientation to the work of ethnobotany, “Ethnobotany on a Roll! Access to Vietnam,” also contributes to an understanding of the impact of individuals with disabilities upon their chosen professions.

Malaysian pianist, Lee-chin Heng, reports as a participant in the “No. 1 Piano Paralympic in Japan,” the first Piano Paralympics held in Tokyo, Japan during January, 2005. The event included 99 musicians with disabilities selected from around the world for their high achievement. The tension between great personal accomplishment and the demands of travel with a disability is manifest in various glimpses of the value often attributed to disability cultures – interdependence.

Michele Sheib moves the dialogue on identity forward with, “Making an Impact: The Benefits of Studying Abroad.” Writing from the Mobility International, USA’s National Clearinghouse on Disability and Exchange, Sheib compares the experiences of ten study abroad alumni with published accounts from the general study abroad alumni population and draws out the implications for identity creation.

### **Travel and Hospitality Industry**

The travel and hospitality industry occupies a gatekeeper role in the universe of travel options for those with disabilities. Marina Flores of Russia observes the hospitality industry from within

the profession. Her contribution on representation of travelers with disabilities, "Optimization of Hotel Reception and Accommodation Service Management for Guests with Disabilities" is based on original research she has undertaken to measure attitudes toward guests with disabilities and their reflection in the behavior of hotel management and staff.

Universal Management is a concept incorporating the seven principles of Universal Design into the policies and processes of business. Australian Peter Rice provides an in-depth overview of Universal Management in an article of the same name and applies it to inclusive tourism in the Australian context.

### **Acknowledgements**

The production of a work such as this Forum is a collaborative effort. I am grateful for the support of the editors of the *Review of Disability Studies*, Steven E. Brown and Megan Conway. Their policy of encouraging submissions from previously unpublished authors attracted me to this project and added to its richness. It has been a privilege to work with each of the authors who contributed their work.

With hindsight the years 2004 and 2005 may be revealed as a turning point in the effort to open the travel and hospitality industry to full participation by travelers with disabilities. Australia, Brazil, and Mexico held national conferences on the topic. Taiwan, Japan, Brazil, Germany, and England held regional or international conferences. It is an auspicious time for *RDS* to bring this dialogue into the heart of the academy with the launch of this Forum.

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## Toward a Global History of Inclusive Travel

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**Abstract:** This paper provides an overview of the development of inclusive travel and tourism, from its origins in the United States and Europe following World War I and II to its current status as an increasingly important and viable movement worldwide. The paper investigates the key roles played by disability organizations, disability rights legislation, technological change, international organizations and pioneers within the travel and tourism industry. Developments are described sector by sector for air travel, ground transport, the cruise lines and the hospitality industry. While the primary historical focus is the U.S., the paper also highlights advances taking place in Dubai, Egypt, India, Japan, South Africa, Thailand and other countries. It concludes with a case study by José Isola of the development of inclusive travel in Peru. Mr. Isola also describes disability conferences that took place in South America in 2004. It is hoped others will begin to investigate the development of inclusive travel in their own countries and regions and contribute to a truly global history.

**Key Words:** inclusive travel, disability movement history, accessible travel

While the history of accessible travel and tourism is intertwined with the disability rights and independent living movements, sharing their triumphs and setbacks, it has its own landmark events, advocacy organizations, heroes and villains. Initially a beneficiary of the struggle for accessible transportation and public facilities and services in North America and Western Europe, tourism that accommodates the needs of

travelers with disabilities has by now become, in the words of the World Tourism Organization, a “motor of accessibility” worldwide (1997). This opinion was echoed by UN ESCAP at the Asia-Pacific Conference on Tourism for People with Disabilities (2000):

“In view of the changing consumer demand, tourism for all is an increasingly important sales argument in a competitive market. At the same time, it can serve as an effective tool in furthering the human rights of people with disabilities in the destination communities.”

The extent to which inclusive travel has become big business has been documented in nationwide surveys by the Open Doors Organization (2002, 2005) in the United States and Kéroul (2001) in Canada. This does not, however, mean this market is now viewed uniformly through the lens of “economic opportunity.” The medical or charity model of disability still holds sway in whole regions of the globe and among many entities and even sectors of the tourism industry, within developed as well as less developed countries. This paper will highlight advances in accessible tourism primarily in the US but also worldwide, concluding with a case study by José Isola of the development of inclusive travel in Peru.

### Beginnings

The earliest forms of travel by people with disabilities most likely were for purposes of pilgrimage and medical cure, often linked to one another. To this day, the Catholic Travel Office, based in Maryland, holds an annual pilgrimage for people with disabilities or illnesses to Lourdes, France, where pilgrims take the healing waters and visit the holy sites. A popular secular center of healing in England was Bath, whose curative powers were recognized long before the Roman arrival in 43 AD. In more modern times, traveling long distance and even internationally for treatment at the most advanced hospitals and rehabilitation centers re-

mains a common experience for both children and adults with disabilities. One such mecca in the US, dating back to the mid-1920s, is the Warm Springs Polio Rehabilitation Centre (now Roosevelt Warm Springs Institute for Rehabilitation), organized and funded in its early years by Franklin Delano Roosevelt (Pelka, 1997, p. 318).

In analyzing precursors of inclusive travel, it is unnecessary to go further back than the World War I and World War II conflicts which impelled governments in the United States and Europe to provide benefits and services including rehabilitation, education and income support to returning veterans with disabilities. In England and France, the war wounded received preferential seating on public transport. In the US, camps for disabled veterans provided recreational opportunities, some of which still exist today such as the Disabled Veterans Rest Camp in Minnesota. Between the two World Wars, charity organizations targeting specific disabilities began to organize summer camps (Pelka, 1997, pp. 240-41). For many children, including those affected by the polio epidemic, these provided a first experience of travel away from home. These facilities were segregated, although, ironically, that very segregation may have helped to foster a sense of disability identity or community so important to the later struggle for equal rights (Heumann, 2003).

Competition in wheelchair sports, especially following World War II, provided another opportunity to travel. Since wheelchair athletics was an important tool in rehabilitation at veterans' hospitals, it was natural that the Paralyzed Veterans of America, founded in 1946, play a leading role in promoting wheelchair athletics and recreation. Sports travel took on an international flavor in 1948 when England's premier veterans' rehabilitation center, Stoke-Mandeville Hospital, organized the first International Wheelchair Games to coincide with the London Olympics. In 1960 the first official Paralympic Games were held in Rome, drawing 400 ath-

letes from 23 countries (Pelka, 1997, p. 235). Regional competitions were also organized such as the Far East and South Pacific Games for the Disabled, first held in 1975 (ILRU 2003b). By the 2004 Paralympics in Greece, the total number of athletes had soared to 3,969, representing 136 nations (Cruise, 2004, p. 16). A lasting benefit of the Paralympics is the boost in accessibility of the host city, which typically makes public streets, hotels, attractions and even mass transit systems wheelchair accessible. In Athens, even the Acropolis now has a wheelchair lift.

As persons with disabilities began to form their own political organizations, their members began traveling to regional and national conferences. Although the earliest such organization, the National Association of the Deaf (NAD), has been holding national conventions since the 1880's, such travel would become a meaningful trend only in the 1940's with the formation of a significant number of disability rights groups including the American Federation of the Physically Handicapped, the National Federation of the Blind (NFB), the Paralyzed Veterans Association and the National Spinal Cord Injury Association (Pelka, 1997, p. 212). The biennial conferences of the NAD now bring together more than 2500 delegates, while attendance at NFB Conventions typically exceeds 3000; and these are just two of the hundreds of disability organizations now holding meetings at the local, state and national level. International disability conferences also draw delegates from every corner of the globe. In 1999, an International Summit Conference on Independent Living, held in Washington, DC, was attended by 110 leaders in disability rights from 50 nations (ILRU, 2003b).

### **The Role of Technology**

Technology plays a key role in the development of inclusive travel. Landmark events in the history of the wheelchair, for example, include the folding wheelchair, patented in 1909, and the Everest and Jennings (E&J) X-frame chair,

patented in 1937, which was “less cumbersome during travel” and could be packed in a trunk. Following the anti-trust suit against E&J by the US Justice Department, settled in 1979, other companies were free to develop lighter, more user-friendly models such as the Quickie, the brainchild of Marilyn Hamilton (Pelka, 1997, pp. 320-21). Off-road, hiking and beach wheelchairs now open up the world of outdoor recreation. The power chair and the three-wheeled scooter merit their own histories. The latter dates back to 1968, when Al Thieme, president of Amigo Mobility, built the first model in his garage for his wife who had developed multiple sclerosis but did not wish to use a wheelchair (Thieme, personal communication, 1999).

After 1946, when US Public Law 663 granted free automobiles to veterans who had lost limbs or been paralyzed in World War II, the PVA became active in publicizing new technologies such as hand controls. By then, automobiles with automatic transmissions, first sold by General Motors in 1940, had become more common (Zames, 2001, pp. 174-75). The development of hydraulic lifts for vehicles would come in the 1950s. Timothy Nugent, who founded the National Wheelchair Basketball Association in 1949, is credited with creating the first hydraulic lift-equipped bus in the US (Pelka, 1997, p. 225).

For persons with sensory impairments, technology was less a factor in the early history of inclusive travel than at present. At many US airports one can now find not only assistive listening systems, volume control phones and TTY's, but also visual pagers and CRT's at the gates giving real-time information. Portable FM systems are improving access in tour groups. New guidelines for the Americans With Disabilities Act of 1990 (ADA) (Access Board, 2004, pp. 235-36) mandate speech output on automatic teller and fare machines, while in future audible signals at crosswalks and even Talking Signs may be required. Because of technological change, access standards cannot remain static.

The Internet has, of course, revolutionized inclusive travel as it has so many other facets of life for persons with disabilities. The ready availability, indeed proliferation, of detailed access information, unthinkable before the 1990s, has made trip planning easier and less expensive and undoubtedly encouraged more people to travel. It has also made it easier for facilities, even in remote locations, to find the technical information they need to improve physical access or locate product suppliers. One of the earliest sites dedicated to inclusive travel is Access Able Travel Source, run by Carol and Bill Randall. Excellent portals for accessible travel now exist in Europe, the UK, Canada and Australia as well.

The global spread of accessibility via technology is another trend worth noting. In hotels with no other tactile or Braille signage, Otis elevators are accessible to guests who are blind and also have lowered control panels. The standardization of access can also be seen in commercial airplanes since there are only a few major manufacturers such as Boeing and Airbus. Of course, the limited extent of accessibility demanded of the airlines by US Air Carrier Access Act regulations, which permit narrow aisles and mandate no accessible lavatory except on multi-aisle aircraft, could be seen as holding back access worldwide.

### **Legislating for Access**

Inclusive travel depends on a broad range of services and facilities from both private and public sectors. Local transportation, private or public, at the origin and destination; bus and train stations, airports and cruise ports; overnight accommodations; restaurants; attractions of all sorts; tours and excursions; and even the public streets and sidewalks as well as telecommunications must be made accessible. Given this list, it is easy to understand why, even in the United States, the process of regulating access in travel and tourism still remains incomplete. One major gap is guidelines for passenger ves-

sels, which may still take the US Access Board some years to finalize. Travelers with disabilities are also waiting for the regulations to implement Air-21, which in April 2000 made foreign air carriers serving the US subject to the Air Carrier Access Act (Workie, 2001, p. 26).

The pattern typical worldwide including the US is for government owned, operated or funded services and facilities to be regulated first. For example, the US Architectural Barriers Act of 1968 applied just to federal construction and Section 504 of the Rehabilitation Act of 1973 to federal programs or activities or those receiving federal financial assistance. Thus, urban mass transit, airports and other federally financed transport facilities were affected first by disability rights legislation. In 1986, the Air Carrier Access Act, which prohibits discrimination by air carriers, was passed with final regulations promulgated in 1990. Only with passage of Title III of the Americans with Disabilities Act in 1990 was discrimination finally prohibited *at the federal level* in public accommodations operated by private entities such as hotels, restaurants, movie theatres, and intercity buses.

Enforcement of disability legislation depends on the creation of legal standards. In the case of the United States, the first architectural access standards were published by the American National Standards Institute in 1961. Developed by a committee which included architects, builders, industry and government representatives and disability rights groups such as the PVA, these specifications became the basis for all subsequent federal access guidelines created by the US Access Board. The ANSI standards also allowed state and local governments to begin enacting their own access codes. The first state code signed into law in South Carolina in 1963 affected only government facilities, but North Carolina's in 1974, developed by universal design architect Ronald Mace, also covered privately owned buildings and facilities except private homes and some industrial structures (Pelka, 1997, p. 26). Prior to the ADA, it

was legislation at the state and local levels that moved access forward in the private sector, including the hotel industry.

At present comprehensive rights-based legislation like the ADA exists in only a few countries. Australia's Disability Discrimination Act became law in 1992, while the United Kingdom's Disability Discrimination Act came into force in 1995 and has been implemented in stages so as to not impose too great a burden on the private sector. While many countries now have legislation in place guaranteeing social inclusion for persons with disabilities, most have significant room for improvement, in implementation of legal standards and enforcement, if not in the laws themselves. In the IDRMs' *Regional Report of the Americas*, only 5 nations were rated "most inclusive": Brazil, Canada, Costa Rica, Jamaica and the US (2004)). A second report on the Asian-Pacific region is scheduled for release shortly.

### **Travel and Tourism Pioneers**

Until the 1970s, few travel or tourism organizations or companies provided or promoted facilities or services to individuals with disabilities. Perhaps the earliest US tour company was Evergreen Travel, based in Lynnwood, Washington, which offered "Wings on Wheels" and "White Cane" tours from 1961 until 1994, when owner Betty Hoffman retired. Because of the lack of accessible facilities, clients on their early wheelchair tours had to endure a lot of lifting and carrying. One popular overseas destination was China and the Great Wall. By the 1980s the company had acquired a lift-equipped bus for tours of the West. Another pioneering firm, Flying Wheels Travel, founded in 1970 by Judd Jacobson, a quadriplegic, and his wife Barbara, is still in business today, offering independent and group travel. For adults with developmental disabilities, Sundial Special Vacations in Oregon has provided travel and recreation opportunities since 1968 and The Guided Tour, founded by



Irv Segal, since 1972. Another pioneer, Wilderness Inquiry, has organized inclusive outdoor adventure experiences in Minnesota's Boundary Waters Canoe Area since 1978.

In Canada, one of the first specialized travel agencies, Handi-Tour, was created in 1977 by Cinnie Noble, who later wrote *Handitravel: A Resource Book for Disabled and Elderly Travelers* (1985). Other pioneering travel agents from the 1970s in the US include Lou and Yvonne Nau, of Nautilus Tours; Joan Diamond, the company's current owner; and Bob Zywicki, of Whole Person Tours, who also published a bi-monthly travel magazine, *The Itinerary*, until his retirement in 1992. In the UK, Chalfont Lines, founded by Terry Reynolds in 1972, remains a leader to this day. Chalfont wowed the industry in 1997 with its \$500,000 "Millenium Executive" coach, designed to be universally accessible and featuring a wheelchair accessible restroom and an assistive listening system. In the Netherlands, Anna Dekker's tour company, Euro-World, dates back to 1977.

Many of these early advocates for inclusive travel were active members of the Society for the Advancement of Handicapped Travel (SATH) (now Society for Accessible Travel & Hospitality), a non-profit educational organization founded in 1976. Its chairman, Murray Vidockler, a travel agent from Brighton Beach, Brooklyn, believed people with disabilities had the right to travel like everyone else and that inclusive travel would become an important market. Mr. Vidockler had previously contributed to the civil rights struggle, chartering 500 buses from as far away as Canada for the March on Washington in 1963, and had also founded the Africa Travel Association in 1975 (Van Horn, 1999, Spring/Summer, p. 5). His new organization, SATH, would set out to convince a highly skeptical travel industry that accessible travel was not only the right thing to do morally, but also monetarily.

The extent to which SATH has achieved its goals is debatable. Certainly over time its decision to remain an all-volunteer organization controlled by family members has limited its effectiveness and size. While the National Tour Association (NTA) and American Society of Travel Agents (ASTA) each awarded Mr. Vidockler its highest honors before his death in 1999, their commitment to inclusive travel remains skin-deep. In 1997 only a hundred ASTA member agencies were specializing in this market (Van Horn, 1997, p. 13). As a result, travelers with disabilities rely much less on travel agents than does the general population (Open Doors Organization, 2002, p. 20). The NTA has been even less responsive. Its members, who primarily provide motorcoach tours, have resisted mainstreaming clients using wheelchairs, even though lift-equipped buses are now mandated and readily available. SATH's main focus since 1997 has been its annual World Congress for Travellers with Disabilities, held in South Florida and designed primarily to educate travel agents.

From the beginning, SATH attempted to raise awareness internationally. Between 1976 and 1984, the Society held conferences in Rome, Amsterdam, Vienna, London and Toronto, as well as Boston, Washington, DC and Los Angeles. The strategy was to induce a spirit of competition among cities as well as countries, while providing agents and tour operators the opportunity to research access and recruit receptive operators in new destinations. At home, SATH served on the advisory committee for the Congressional Caucus on Travel and Tourism and worked closely with the US Travel and Tourism Administration (USTTA), a now defunct branch of the Department of Commerce. In 1985, SATH and the USTTA hosted a tour of the US for British and German journalists specializing in disability issues (Davis, 1986, p. 1). The USTTA, along with Greyhound Lines and ASTA, also funded publication of a SATH booklet, "The United States Welcomes Handicapped Visitors" (Snider, 1985). According to author

Harold Snider, the booklet was later translated into 11 or 12 languages, with 500,000 copies distributed. Snider, who is blind, was a SATH officer from 1980 to 1986 and previously served as the first coordinator of disability programs at the Smithsonian Museum.

Three other organizations important to the development of inclusive travel were also founded in the 1970s. In the UK, The Royal Association for Disability and Rehabilitation (RADAR), a cross-disability organization dedicated to social inclusion, was formed in 1977 and Holiday Care Service (now Tourism for All UK) in 1979. Both still play important roles in educating the travel industry and consumers. RADAR is responsible for creating the National Key Scheme and publishing access guides such as *Holidays in Britain and Ireland* (2004), which has been issued annually for more than 20 years. In Canada, Kéroul was created in 1979 by Andre LeClerc. Kéroul, like SATH, works in partnership with the tourism industry. Initially focused primarily on Quebec, the organization over time has taken on both a national and international leadership role, addressing issues such as universal access standards and market statistics.

### **Access to the Skies**

While SATH and the other non-profits within the tourism sector advanced the cause via gentle persuasion, American disability organizations began turning to stronger tactics, including sit-ins and lawsuits. The history of the rights movement of the 70s and 80s (Pelka, 1997; Scotch, 2001; Shapiro, 1993; Treanor, 1993; Zames, 2001) need not be retold here beyond identifying some of the organizations and events of particular note in the development of inclusive transportation.

In terms of air travel, the most influential role was played by the Paralyzed Veteran's Association (PVA), whose law suit versus the Department of Transportation was heard by the Supreme Court in 1986. The PVA contended

all airlines benefited from federal subsidies at airports including the use of federally paid air controllers, and therefore were subject to Section 504 of the Rehabilitation Act of 1973, which provides that:

“No otherwise qualified handicapped individual in the United States...shall solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activities receiving Federal financial assistance” (p. 153).

Travelers with disabilities, especially those using wheelchairs, were being discriminated against: denied boarding unless accompanied by an attendant, required to produce medical certificates, denied choice of seating, and subject to quotas per flight. The Civil Aeronautics Board's final regulations in 1982 addressed some of these issues, but only for commuter or regional airlines receiving direct federal support, not the major airlines. Louise Weiss' *Access to the World* provides a fascinating snapshot of the travel industry in 1986, with pages of tables on the differing airline policies. Although the Supreme Court would rule against the PVA, the storm of publicity surrounding the case finally led Congress to decide having some airlines covered by federal legislation while others were not was unacceptable. The result was the Air Carrier Access Act of 1986.

In November 1986, the Canadian Transport Commission also came to the defense of travelers with disabilities, ruling that Air Canada and the other national airlines could no longer require an attendant for passengers with disabilities. Australia's Air Carriers Access Act dates to 1986 as well.

### **Accessible Mass Transit**

The US battle for accessible mass transit and intercity buses was especially heated, with the PVA, American Coalition of Citizens with

Disabilities, Disabled in Action and ADAPT, founded in 1982, playing key roles. A major concern was that riders with disabilities not be relegated simply to alternative transportation systems such as paratransit, which had proliferated during the 1970s. Under DOT regulations implementing Section 504 of the Rehabilitation Act of 1973, it was up to local transit authorities to decide whether to provide accessible mainline service or to create a separate system to serve residents with disabilities. Although a low floor, wide door “Transbus,” designed using federal money, made accessible mainline bus systems feasible, local authorities with few exceptions opted for paratransit. These separate services required users to book their rides in advance, provided a limited number of rides per month during limited hours of service and usually served a smaller geographic area than mainline transit. They also were plagued by long waiting lists and unreliable service. Not surprisingly, disability advocates felt that the community would, in large part, be better served through mainline transit. In the end, the disability organizations prevailed, which meant that all new city buses would become accessible, as well as trains, light rail systems and even, in time, older subway systems such as New York’s. The provisions of the ADA also mandate paratransit services for those unable to use buses and subways (Pelka, 1997, pp. 11-13, 237-38, 253-55).

The motorcoach industry, long at odds with the disability community and pleading poverty, managed to stave off access requirements until 1998. When the Department of Transportation published the final rule for over-the-road buses, the American Bus Association immediately filed a lawsuit contesting its legality. ADAPT, which waged a two-year “We Shall Ride” campaign against Greyhound, responded by sending 700 members to shut down the ABA’s Washington DC office (ADAPT, 1998). Although the US District Court rejected the ABA suit, the organization on appeal did manage to have a compensation provision for riders struck down (Workie, 2001, p. 26).

Under the final rule, a 48-hour advance notice is required for lift-equipped service, which will continue until large companies like Greyhound achieve 100% accessibility of their fleets, currently set for 2012. Because small companies are not required to purchase lift-equipped vehicles, the 48-hour advance notice for them is permanent. The availability of lift-equipped service, especially important for rural areas and for lower income riders in general, means individuals with restricted mobility can now join mainstream bus tours. But neither charter nor fixed-route companies are as yet reaching out to this new potential clientele.

Aside from the movement of technology from one country to another, it may not seem there is much global effect in advances in ground transport. Sometimes, however, just the example of achievement can lead others to demand similar accommodation, even where financial resources are quite different. The recent creation of fully accessible subway systems in New Delhi and Bangkok would certainly indicate this is the case.

### **The Cruise Industry**

In contrast to other tourism sectors, the attitude of the cruise industry, largely market driven, has been positively welcoming. Already by 1967, Cunard’s QE2 was designed to accommodate passengers using wheelchairs, with 4 staterooms for wheelchair users (Weiss, 1983, p. 76). By the mid-1980s, Princess Cruises and Holland America were also buying, retrofitting and building accessible ships, with Royal Caribbean and Celebrity Cruises joining the competition in the 1990s. Between 1999 and 2002, the number of wheelchair accessible cabins on ships sailing in the Caribbean jumped from 670 to 1,076, a 60% increase in just three years (Wade, 1998, section 5, p. 2). The needs of passengers with sensory impairments are also being met through use of FM systems in theatres, communication and alerting devices in cabins, sign language interpreters, Braille and tactile signage

and accommodations for service animals. Oxygen canisters and concentrators can be brought aboard, special diets are available and one can even arrange for kidney dialysis while at sea.

The picture is not, however, entirely rosy. Accessibility and attitude vary widely among companies serving the US market, which has led to several vitriolic lawsuits. Because the cruise ships are almost all foreign flagged vessels, there was disagreement on whether new passenger vessel guidelines, released in draft form by the Access Board in November 2004, would apply without additional legislation from Congress. Following contradictory rulings at the district court level, the Supreme Court agreed to hear the case of *Spector v. Norwegian Cruise Lines*, ruling in June 2005 that the civil rights protections of the ADA do indeed apply to foreign-flagged ships serving US ports. However, the extent of structural modification may be limited to what is “readily achievable” and must be decided on a case to case basis.

Like the airlines, cruise companies have an international impact on access, delivering passengers with disabilities into ports of call where their local counterparts are not integrated into the society or viewed as viable customers. To provide an equivalent service and avoid complaints over the lack of accessible tours or attractions, cruise lines have become advocates for disability access in areas such as the Caribbean. Since 1999, the Florida Caribbean Cruise Association has sponsored workshops on accessible shore excursions at its annual conference. In St. Thomas, Princess Cruises contributed a wheelchair lift at Mountain Top Observation Deck, a stop on the new lift-equipped trolley tour. Acapulco, Mexico, an important stop for cruise ships from California, also has accessible trolleys for city tours, while Barbados and Curacao have lift-equipped motorcoaches. All over the Caribbean, investments are being made in accessible cruise ports and airports, impelled but also funded by the region’s largest industry, tourism.

## The Hospitality Industry

Because the large hotel chains have a global presence, they too can impact access in the far corners of the world, should they choose to do so. Travelers with disabilities are known for brand loyalty so it would make sense to create brand standards for accessibility, as for other facilities and amenities. This indeed is the policy for a number of major chains, such as Wyndham, Hyatt, Radisson and Holiday Inn. Oberoi in India and Amari in Thailand are regional leaders in this regard. Of course, the spread of legal access standards is also preventing multinational firms from backsliding outside their home markets. This is an issue as well for restaurant chains such as McDonald’s, whose inaccessibility in some foreign countries has angered American travelers with disabilities.

In the US, one of the early leaders in hotel access was Holiday Inn, who set a policy in 1964 of creating one barrier-free room per 100 in each of its hotels. By 1978, 625 of its 1700 locations had such a room (Weiss, 1983, p. 149). As a result, in this period before the ADA, the chain became a favorite among travelers with physical disabilities. In 1985 the company also began installing visual alert systems for guests with hearing loss, and by early 1986 had these emergency alarms in place at 150 of their properties (Holiday Inns, 1986, p. 4). Although Holiday Inn ran afoul of the Department of Justice in 1998 because of reservations policies and access violations, it has since tried to regain its earlier reputation.

In many destinations worldwide it is becoming easier to find relatively accessible hotels, resorts and even guest houses--for those using wheelchairs, that is. For individuals who are blind or deaf, little is yet being done at all outside the most developed countries. Even in the US, the needs of those with hearing loss have taken a back seat. A number of factors could contribute to this inequality: the invisible and variable nature of the disability, communication

barriers, a tendency by many not to self-identify and historic differences in activism and media coverage, to suggest a few.

### **The Impact of International Institutions**

The International Year of Disabled Persons, 1981, was a watershed year for both disability rights and inclusive travel. The United Nation's 1975 Declaration on the Rights of the Disabled had already brought about a jump in awareness. The UN's intent in proclaiming first a Year and then a Decade of Disabled Persons (1983-1992) was to encourage concrete commitments on the part of governments and international organizations (Pelka, 1997, p. 168). It also led to the creation of national disability organizations in many countries, from Thailand to the UK, South Africa and Brazil (ILRU, 2003a). In the US, Susan Sygall and Barbara Williams in 1981 founded Mobility International USA, a non-profit organization dedicated to international educational exchange, leadership development and travel by persons with disabilities. At a conference in Singapore in late 1981, attended by 400 persons with disabilities from 51 nations, Disabled Peoples' International also was founded (Pelka, 1997, p. 103). And in the UK, the British Tourism Authority hosted a first-ever familiarization tour for disability travel specialists.

Another landmark in 1981 was the publication by the International Air Transport Association of "Resolution 700-Acceptance and Carriage of Incapacitated Passengers." This agreement among IATA member airlines harmonized on a worldwide basis the regulations and procedures applied to passengers with disabilities and medical illnesses (1981). It was, however, voluntary and not enforceable. In 1993, Resolution 700 was revised to bring it into conformity with the US Air Carrier Access Act (IATA, 1993). In recent years, IATA has also been conferring with the European Community which would like to make its own voluntary code of

1992 legally binding for member states (IATA, 2002; ECAC, 2001)

In 1985 the World Tourism Organization (WTO), an intergovernmental body formed by UN Charter in 1975, officially recognized the importance of inclusive travel by accepting SATH as an affiliate member. The following year a working party on disability travel, chaired by SATH, was formed. In 1991, the General Assembly unanimously approved a resolution entitled "Creating Tourism Opportunities for Handicapped People in the Nineties," written largely by SATH's executive director, Peter Shaw-Lawrence (WTO, 1991).

WTO's commitment to inclusive travel was reaffirmed in 1999 by Articles 2 and 7 of its "Global Code of Ethics for Tourism," which state that tourism activities should promote the rights of people with disabilities and "tourism for people with disabilities should be encouraged and facilitated" (WTO, 2001). At a practical level, the WTO addresses the issue of accessibility as a "quality determinant" along with "safety and security, hygiene, transparency and harmony of the tourism activity with its human and natural environment." The organization's current definition of accessibility employs the terminology of universal design (2003).

This determinant requires that physical, communication and service barriers must be done away with to allow, without discrimination, the use of mainstream tourism products and services by all people irrespective of their natural and acquired differences, including people with disabilities.

In a "Tourism for All" Forum in Barcelona in 2004, Henryk F. Handszuh, Head of Quality and Trade in Tourism, called for "the design of a set of technical specifications that are shared at the world level," noting the International Organization for Standardization is now interested in "carrying out the worldwide coordination of standards for tourism accessibility" (WTO 2004, ISO). This is a goal long championed by

SATH and Kéroul which now may actually be within reach, thanks to WTO's support.

Nowhere has the impact of the United Nations been stronger in the field of disability rights and inclusive tourism than in the Asia Pacific region. Here the governments made a "collective commitment to improving the lives of persons with disabilities," declaring the period 1993-2003 as the Asian and Pacific Decade of Disabled Persons. "This regional initiative focuses on promoting the inclusion of persons with disabilities in mainstream society and mainstream development programs," including access to transportation (UN ESCAP, 2000). UN ESCAP Pilot Projects to improve the accessibility of urban areas have been carried out in Beijing, New Delhi and Bangkok, with lasting impacts in terms of awareness, legislative developments and expansion to other areas (Parker, 2001, pp. 103-115). The importance of accessibility for sustainable tourism has also been directly addressed, with the first Asia-Pacific Conference on Tourism for People with Disability held in Bali, Indonesia, in September 2000.

Kenneth J. Parker notes of Singapore: "The demographic trend of increasing numbers of elderly persons is a major concern to the authorities and it is probably this, more than anything else, that has brought more attention to inclusivity in recent years" (Parker, 2001, p. 107). This is certainly true for Japan, which boasts the world's oldest population and has become a major center for universal design. The Japanese have played a critical role in raising awareness, funding training and providing technical expertise throughout the region. Key institutions include the Japan International Cooperation Agency (JICA) and DPI-Japan, founded in 1986, which has successfully campaigned for accessible transport and legislative changes in Japan and provided training locally, regionally and now globally. As part of the 2nd Decade of Persons with Disabilities in Asia and Pacific Region (2003-2012), JICA has funded a 5-year training project by DPI-Japan to empower and

mainstream persons with disabilities in Southern Africa (DPI-Japan, 2004). The World Bank has also begun funding DPI-Japan workshops on inclusive education in Latin America.

The World Bank's new focus on inclusion was signaled by the appointment of Judy Heumann in June 2002 as their first advisor on disability and development. Ms Heumann was founder in 1970 of Disabled in Action and co-founder in 1983 of the World Institute on Disability. Over time the World Bank's focus has shifted from economic development pure and simple, which often brought about even greater income inequality, to poverty alleviation and now at last to the realization that the latter cannot be achieved unless persons with disabilities are also brought into the mainstream. This new approach is due in part to the influence of James D. Wolfensohn, President of the World Bank, who formerly was chairman of the board of the International Foundation of Multiple Sclerosis Societies. Current projects supported by the World Bank include accessible rail and bus-based mass transit systems in Brazil, Chile, Colombia and Peru.

### **Best Practice in Travel and Tourism**

In 2003, Kéroul produced a document for the Asia-Pacific Economic Cooperation entitled *Best Practices in Tourism Accessibility for Travellers with Restricted Physical Ability*, providing details on projects carried out in Australia, Canada, Hong Kong, Japan, Mexico, New Zealand, the Philippines and the US. Some of these organizations are described below.

In the United States, Accessible San Diego (ASD) offers a unique service to both visitors and residents with disabilities, not only providing access information online and via a print guide, but also working to make San Diego one of the country's most inclusive cities. Thanks to their efforts, the trolley tours and sightseeing boats are accessible and there are even power beach wheelchairs available free at several local

beaches. Another ASD initiative was the “2 for 1 Pass” allowing visitors with disabilities to bring a companion to many of the area’s local attractions such as the San Diego Zoo.

Also based in California is Access Exchange International (AEI), a non-profit organization that promotes accessible transportation worldwide through workshops and publications. *Mobility for All* (Rickert, 1998), AEI’s guide to the fundamentals of accessible transportation, is available online at the website of the Independent Living Institute ([www.independentliving.org/mobility](http://www.independentliving.org/mobility)) and has been translated into Spanish, Japanese, Russian, Portuguese and Bahasa Malay. A second publication, *Making Access Happen* (Rickert, 2003), is geared to advocates and planners.

Open Doors Organization (ODO), a Chicago-based non-profit founded in 2000, has drawn media attention and raised industry awareness via its groundbreaking studies of disability travel, conducted in 2002 and 2005 by Harris Interactive. Thanks to this research, hoteliers, restaurateurs, airlines, car rental agencies and other suppliers now have reliable data on which to base investment decisions, as well as details on the extent and types of barriers that still remain. In 2002, ODO estimated that revenues from the US disability travel market could easily double from the current level of \$13.6 billion per year if certain needs were met and obstacles removed. To assist with this process, ODO works with a growing list of corporations in travel and hospitality. In 2006, ODO will produce an access guide for Chicago and host a symposium for the airline industry, among other projects.

In India, two organizations are making an impact on the accessibility of tourism facilities. The National Centre for Promotion of Employment of Disabled Persons (NCPEDP) in 2001 carried out a six-month project, funded by the U.S. Embassy, to raise awareness of the need to make India’s historic monuments accessible. The

issue came to the forefront when Professor Stephen Hawking visited Delhi in January, 2001. When the Archeological Survey of India (ASI) refused his request, NCPEDP organized a media campaign to pressure ASI to make four sites accessible. Temporary ramps were installed and local wheelchair users were able to visit the Red Fort and Qutub Minar for the first time. Since the larger issue was permanent access, NCPEDP continued to lobby until ASI agreed to make two dozen monuments accessible including the Taj Mahal. The NCPEDP project consisted of detailed audits of four sites—Taj Mahal, Red Fort, Jaipur City Palace and Sarnath—and a workshop for architects and designers, presented in conjunction with the Council of Architecture. Laurel Van Horn, then executive director of SATH, assisted with the site inspections and training. Thanks to lobbying and technical assistance from NCPEDP, the Craft Museum in Delhi also constructed a ramp at its main entrance in 2002. Javed Abidi, executive director of NCPEDP, has also won a case in the Supreme Court forcing the Airport Authority of India to provide mobile lifts at the major metropolitan airports.

A second Indian organization, Samarthyaa, succeeded in improving access at another popular tourism attraction in Delhi, Dilli Haat, a village-style craft market. The group has also approached the Youth Hostels Association of India (YHAI) to request their entrances and at least one room per hostel become barrier-free. The National Chairman of YHAI, as a beginning, has approved the provision of a ramp and lift at the International Youth Hostel in New Delhi (UN ESCAP, 2000).

In Thailand, the city of Pattaya is a leader in accessibility, due in large part to the influence of the Redemptorist Centre, which trains young people with disabilities in computers and electronics. This seaside resort city now has an accessible boardwalk and barrier-free attractions and hotels, the most accessible of which is the Redemptorist Centre guesthouse with its 48

rooms with roll-in showers. Students have created an online access guide for Pattaya ([www.access2thai.com](http://www.access2thai.com)) and one graduate has opened a tour company using lift-equipped vehicles. Each year the Centre hosts international wheelchair athletes who participate in the Pattaya Marathon, an event sponsored by the Tourism Authority of Thailand (TAT).

TAT has taken an active interest in accessible tourism for a number of years and was the principle sponsor for the UN ESCAP project in Bangkok. Sethaphan Buddhani, former director of TAT in New York (TATNY), has been the main proponent of inclusive tourism within TAT since serving as director in Pattaya. He credits his awakening to a sensitivity awareness course he took in Japan. In 2003, TATNY sponsored a Barrier-Free Thailand project, led by Laurel Van Horn, which brought in American and Canadian access experts and tour operators to meet with government officials, conduct access audits and provide training to hoteliers, tour operators and tourism students. The goal of creating an access guide for Thailand has since been sidelined due to funding constraints, but the project did lead to the production and circulation of a detailed report (Van Horn, 2004).

National tourism boards can play a critical role in raising awareness, setting access standards for the sector, gathering and disseminating access information and in promoting the destination as welcoming to all. In South Africa, the tourism board, SATOUR, has been actively involved in accessible tourism since the early 1990s, working in conjunction with Disabled People of South Africa and later the South Africa Federal Council on Disability. Not only are hotels and attractions in the main cities accessible, but also smaller guesthouses and even camping facilities in the national parks (Van Horn, 2002a, pp. 21-22). A growing number of tour companies offer group and independent excursions via adapted vehicles. One operator, Epic Enabled, uses a lift-equipped truck for their wildlife safaris (Krimberg, 2002, p. 23).

Dubai is another success story in inclusive tourism, with the Department of Tourism and Commerce Marketing playing a key role. Because so much of the infrastructure is new and because the awareness was present to build it accessible to all, Dubai is a very welcoming destination. Even the Burj Al Arab tower, the symbol of modern Dubai, has an adapted suite with its own private elevator. Ground transportation in 2002 was a weak link and little was being done for guests with sensory impairments but, given the pace of change in this dynamic destination, these limitations will no doubt be addressed in the near future (Myers & Van Horn, 2002, pp. 12-13).

In Egypt, the Ministry of Tourism is working to improve access and in 2002 invited a team of access specialists (Van Horn 2002b, pp. 6-9, 26) to see the results. Mobile lifts are in place in airports, the newly developed beach resorts of Hurghada and Sharm-El-Sheik have excellent access, and even historic monuments such as Luxor Temple are now being ramped. The latest development is an accessible cruise ship on the Nile, which Flying Wheels tours already made use of in Fall 2004. Ground transport is also improving, with tour operators now offering adapted vans with ramps.

Finally, Peru provides an interesting example of the important role that a national tourism board can play, working hand in hand with disability organizations and tourism providers, to raise sectoral awareness and stimulate concrete change. It also illustrates the difficulty of maintaining the commitment over time, as governments and personnel change.

### **PromPerú's "Tourism for All" Program**

In 1998 Peru's national tourism board, PromPerú, developed a program to address accessibility and services for people with disabilities. It was initiated by a non-disabled tour operator, Juan José "Pepe" Lopez of Apumayo Expediciones, who dreamed of opening the riches



of Peru to travelers with disabilities. When he met Sharon Myers and Laurel Van Horn from SATH in 1997 at the American Travel Market in Orlando, he decided to actualize his dream. It took him a year to convince PromPerú and other local suppliers to sponsor the first study tour that took place in April 1998.

At the time, Peru's General Law of People with Disabilities was under consideration in the Peruvian Congress, and therefore the issue of the rights of disabled people was in the midst of a nationwide discussion. It was also fortunate that Beatriz Boza was then president of PromPerú, as she had studied in the US and knew from experience the importance of people with disabilities as a market segment.

Participants on the first tour included Sharon Myers, a SATH member who uses a wheelchair; Paula Bonillas, editor of *Hearing Health*, who is deaf and has a cochlear implant; and Laurel Van Horn, editor of *Open World*. The group also included a Peruvian with a disability, José Isola, then using crutches due to polio. The group was accompanied by Pepe Lopez from Apumayo Expeditions and Rosario Griffiths from the Sonesta Hotel chain, which hosted the group in Lima, Cusco and the Sacred Valley. The group also visited Paracas, home of the National Marine Reserve.

The project had several goals: to inspect hotels, attractions, and means of transport in the country's most popular areas; make recommendations on how to improve accessibility; provide hands-on training for the Apumayo staff, and begin generating publicity in the American disability press as well as local media. On all counts the trip was a success despite the diverse needs of the group's members and the lack of physical access. Virtually every means of transport was tried--vans, mini-buses, motorboats, rafts, trains, planes and even a helicopter. The group saw sea lions in the Ballestas Islands, attended a Palm Sunday mass in Quechua, the language of the Incas, rafted down the Urubamba River

and even climbed Machu Picchu. Back in Lima the PromPerú staff including Alessia Di Paolo, who would later direct the project debriefed the group for hours, gleaning every detail.

In December, 1998, Sharon Myers and Laurel Van Horn returned to Lima for a disability arts conference, with performances by theatre groups from Mexico, Spain, France, Argentina and Peru. Once again, disability issues made the front page in the Lima press. The visit allowed Sharon and Laurel to meet again with José Isola, Pepe Lopez and Alessia Di Paolo, who was then preparing the PromPerú report on the disability travel market (PromPeru, 2001). Most importantly, Sharon brought José a copy of the ADA Access Guidelines (U.S. Access Board, 1991), which led him to start fighting for an update of Peru's own access code, in effect since 1978. His translation of ADAAG (a Spanish version is now available from the U.S. Access Board—see Resources) became a draft proposal to Peru's Ministry of Housing and Construction. After more than two years of work and an immense effort to convince the authorities of the need for such a reform, the revised Peruvian Accessibility Guidelines were ready in August 2000 (MPS, 2001). These new guidelines, in effect since February 2001, insure that all new construction in Peru will be accessible to individuals with mobility and sensory impairments.

In October, 1999, PromPerú published its report, "Tourism for People with Disabilities: A Growing Market," and to promote the study held two conferences in Lima and Cusco. Beatriz Boza, president of Prom Peru, and Carlos Zuñiga, president of the Peruvian Chamber of Tourism (CANATUR), shared the stage with Pepe Lopez, Sharon Myers and Laurel Van Horn. Also speaking were Andre Leclerc and Patricio Hernandez of Kéroul, which now joined SATH as international consultants on the project. The response to these meetings was overwhelming. More than 300 attendees crowded the conference room in Lima, with another 50 watching the proceedings on a television outside. More

than 100 also turned out in Cusco, where the city's mayor himself took the podium. That same week Pepe Lopez's accessible tourism project received the prestigious "Award for Creative Entrepreneurship" from Peru's University of Applied Sciences, drawing even more media attention.

While in Peru, Sharon Myers and Laurel Van Horn were invited by Rainforest Expeditions to inspect their ecotourist lodge, Posada Amazonas, located in the Madre de Dios district and reachable only by motorized canoe. Here the challenge of getting up and down the muddy riverbanks proved even more formidable than Machu Picchu, but Sharon had brought along a rescue device called a Lifeslider which made the task possible, if not accessible. Since the visit, the lodge has added boardwalks between the buildings so that once on site, wheelchair users can move independently.

Back in Lima, José Isola introduced the two visitors to a gathering of Peru's leading disability activists, including Pedro Chavez and Susana Stiglich, founders of a new, influential cross-disability organization, Asociación Pro Desarrollo de la Persona con Discapacidad (APRODDIS). APRODDIS is the first Peruvian NGO to receive grants and funding from international agencies in the USA, Canada, Great Britain and Japan. To date they have held a series of international conferences and produced a number of outstanding publications on disability issues.

Having raised sectoral awareness with its report and conferences, PromPerú decided in September 2000 to undertake a more ambitious project which would focus on training and generate two tangible products: an 85-page training manual (PromPerú et al., 2000) and an access report, produced in both Spanish and English (PromPerú, 2001). This second study tour included project director Alessia di Paolo from PromPerú; Guy Derý from Kéroul, a quadriplegic; Laurel Van Horn from SATH; José Isola representing CONFIEP, a national business or-

ganization, and Francisco Vasquez, a blind Peruvian who was then president of CONADIS, a governmental body representing the interests of people with disabilities. Accompanying the group were Fernando Sotomayor from Lima Tours and Ghyslaine Busby, Guy's assistant.

During the grueling trip which lasted a full month, the group visited five cities--Cusco, Aguas Calientes (Machu Picchu), Lima, Trujillo and Iquitos; inspected over 100 hotels, restaurants, shopping centers, museums, tourist attractions and airports, and trained over 1,000 tourism employees and students, as well as government officials. Almost every service including hotel rooms, meals and transportation was donated by private companies in exchange for employee training, advice on improving accessibility, and a listing in the access report. This not only made the project affordable for PromPerú but also guaranteed active participation. The training sessions were also attended by local people with disabilities.

This particular visit to Machu Picchu became a media event. José Isola and his wheelchair were carried up all the way to the highest part of the archaeological site so that he could accomplish a lifelong dream: to touch the Intihuatana, the Inca's solar clock completely carved out of stone. This adventure was shared with Francisco Vasquez, the blind member of the group, who spent over 45 minutes touching the stone to "see" every single corner of it. On their arrival, they were surprised by TV cameras and journalists who were there because the huge stone had recently been damaged during the filming of a TV commercial. Suddenly the whole attention of the media turned to them. The coverage was aired on national and international TV that same night.

After the tour, Alessia Di Paolo, José Isola and Laurel Van Horn turned the information they had gathered into the *First Report on Accessibility in Peru for Tourists with Disabilities* (PromPerú, 2001). The report was presented to

the international public at SATH's Fifth World Congress in Fort Lauderdale, Florida in January 2001. The Spanish version was presented to the President of CANATUR at a public ceremony and press conference in Lima, Peru, that March.

In November and December 2001, PromPerú, CONFIEP, CONADIS and the Ministry of Housing and Construction joined together in a project to audit accessibility in over 100 cinemas and theatres in Lima. The resulting publication, "Report on Accessibility in Theaters and Movie Houses in Lima," was presented to the public in late December of that year.

Although the products created by PromPerú between 1998 and 2001 were high quality and admired wherever they were presented, nonetheless at the end of 2001 the whole project was discontinued, since the new officer in charge did not like the image of people with wheelchairs roaming around the ruins of Machu Picchu. However, individual companies in the private sector have continued the initiative, relying on their own money or charitable contributions from a few sponsors.

Since 2003, Nuevo Mundo Viajes, Peru's second largest travel agency, has developed a department to handle travelers with disabilities, both inbound and outbound. Over the next two years this separate section will disappear once all staff members learn how to handle the special needs of these customers. In 2004 José Isola and his associates held training sessions at Nuevo Mundo's Cusco office for guides handling groups to Machu Picchu. They have also provided training for Orient Express, which runs the Hotel Monasterio in Cusco and the Machu Picchu Sanctuary Lodge, as well as the new Hiram Bingham luxury train between Cusco and Machu Picchu. For 2005 they plan to work with two lodges in the Amazon jungle in Northeast Peru and in the Manu Natural Reserve.

## Recent Conferences in Latin America

These efforts to create inclusive tourism in Peru have been complemented by the work being done in other countries of the region. In 2004, three important congresses have been held. The "First Virtual Ibero-American Congress on Tourism for People with Disabilities: Tourism for All," was organized in Argentina by the Tourism for All Foundation. Papers by representatives of Argentina, Costa Rica, Spain, Uruguay and Venezuela were presented, motivating an interesting cyberspace debate throughout the month of October.

The second event was the, "Ibero-American Congress on Tourism for People with Disabilities: Consumer Market for Tourism without Barriers," which took place in Canela, Brazil. Speakers from Argentina, Brazil, Peru, Spain and the United States gathered for three days to learn from each other's experiences. Especially interesting were the presentations by Martin Aranguren from Entre Rios, Argentina, on "Tourism Alternatives for Blind People" and José Ignacio Delgado from Tenerife, Canary Islands, on Mar Y Sol Hotel, a totally accessible facility.

This last presentation motivated a discussion about whether or not one should create specially designed hotels only for people with disabilities. This is still the Spanish way of dealing with people with disabilities: separate housing, specialized hotels and other specialized facilities. Most will not agree with this approach but it sometimes proves useful. In April 2003, the World Bank and the European Community organized the European Congress on Independent Living. The Mar y Sol and nearby Mare Nostrum Hotel complexes were the only locations in all Europe that could comfortably receive 400 people with disabilities, more than 100 of them wheelchair users needing adapted rooms.

Finally, Adaptive Environments' bi-annual conference on universal design, "Designing for the 21st Century III," was held in December 2004 in Rio de Janeiro. For the first time

ever, the event included a full day, pre-conference workshop on “Universal Design and the International Travel & Hospitality Industry,” organized by Scott Rains, a resident scholar at the Center for Cultural Studies, University of California Santa Cruz. This international workshop included presentations on inclusive tourism advances in Israel, Greece, the US Virgin Islands, the US and Brazil. In her discussion of the Rio City Universal Design Project, Regina Cohen, from the Federal University of Rio De Janeiro, addressed the tourism linkages of this urban make-over, which conference attendees had the opportunity to view first-hand. The complete contents of the Conference Proceedings are available online (Adaptive Environments, 2005).

### Conclusion

Although relatively recent in origin, the movement for inclusive travel is now underway to some degree in most countries worldwide. The growing importance and competitiveness of the tourism industry combined with the aging of the population in regions supplying most of the world’s tourism demand makes a compelling economic argument for creating facilities and services accessible to all. The global spread of the disability rights and independent living movements is also heightening awareness and leading to legislative changes that are beginning to impact private as well as governmental sectors.

While a “seamless” travel experience largely remains a goal rather than a reality even in the United States, tangible improvements in access are nonetheless taking place every day. Specialized tour operators in many countries now make travel possible for domestic as well as foreign tourists with disabilities. Over time, as public transportation, accommodations and attractions become routinely accessible, inclusive travel will become more and more mainstream, no longer a case of “special needs.”

This paper has highlighted many individuals, organizations and companies working toward this ultimate goal. Due to space limitations, there are many, many more who have not received mention. Now that this fascinating topic has been broached, it is hoped others will begin to investigate the development of inclusive travel in their own countries and regions and contribute to a truly global history.

**Laurel Van Horn** (B.A., Bryn Mawr College, M.A., New School for Social Research) has worked in the field of disability travel since 1987. She was formerly executive director of SATH and editor of *SATH News* and *Open World for Disability and Mature Travel*. She has also taught in the Travel and Tourism program at Baruch College in New York City. Laurel is currently research director and editor for Open Doors Organization and also writes a travel column for *Able News*. She can be reached at [laurel@opendoorsnfp.org](mailto:laurel@opendoorsnfp.org).

**José A. Isola** has been involved in advocating for the improvement of accessibility, including writing the 2001 modification of Peru’s Accessibility Guidelines, and promoting disability travel in Peru since 1998. He has written several articles on accessible tourism in Peru for Access Able Travel Source, the International Institute on Disability in Washington DC and Open World Magazine. José is currently the President of the Peruvian Polio Society. He can be reached at [joseisola@yahoo.com](mailto:joseisola@yahoo.com).

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# Invention of Accessibility: French Urban Public Transportation Accessibility from 1975 to 2006

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**Abstract:** This paper discusses accessibility policies of the French Ministry of Transportation and the two urban mass transit companies in France. One company is the *Régie Autonome des Transports Parisiens* (RATP), France's leading urban mass transit company. The second transit company, which is much smaller than RATP, is the *Société des Transports Poitevins* (STP). Both company's actions illustrate policies pursued for almost the last thirty years. This article will focus on RATP. The two aims of this article are to show, a) how new solutions for facilities of public transportation networks are linked to the way stakeholders view disability, and b) how changes in this view have reflected stakeholders' moves to promote their idea of accessibility and disability.

**Key Words:** public transportation, disability history, accessible travel

## Introduction

In France, accessibility to the public transportation system is enshrined in the 1975 Disabled Policy Act. Despite the Act, public transportation accessibility for individuals with disabilities is still a recurrent topic in public debate, and many voices openly criticize the inaccessibility of public places (the Paris Metro is the example most frequently given).

Nonetheless, numerous solutions have been rolled out since 1975. This was highlighted in a study<sup>1</sup> of facilities that had either been recommended or installed as part of the accessibility policies of the French Ministry of Transporta-

tion and the two urban mass transit companies in France. One company is the *Régie Autonome des Transports Parisiens* (RATP)<sup>2</sup>, France's leading urban mass transit company. RATP covers the whole of Paris and its suburbs and is used for 2.6 billion trips per year. The second transit company is the *Société des Transports Poitevins* (STP). It is much smaller than RATP, handling 1.2 trips per year and covering the ten communities in the *Communauté d'Agglomération de Poitiers* (CAP, Poitiers metropolitan area), the authority responsible for organising transportation. Due to these factors, the company is representative of urban transit operators in general. Both companies illustrate the policy pursued for almost the last thirty years. This article will focus on the RATP. The two aims of this article are to show how new solutions for the facilities of public transportation networks are linked to the way stakeholders view disability and how changes in this view have reflected stakeholders' moves to promote their idea of accessibility and disability.

In 1975, the dominant paradigm of disability was based on a medical and functional view, requiring individual responses peculiar to the person identified as disabled. Disabled people were considered from the standpoint of their medical characteristics. A person has an impairment – for instance, he or she is paraplegic and cannot walk – therefore, that person is disabled. This paradigm, which associated disability with a medical, individualized view, underpinned the drafting of the 1975 Act (Chauvière, 1998 & 2000; Chapireau, 1988 a & b). It prompted legislators to propose special solutions of accessibility to help only disabled people in the medical sense (for instance, lifts reserved for them, special transportation only for disabled people).

In 2006, the representation of disability has diversified. Alongside the medical, individualized view, another approach has developed out of an environmental, perhaps even political, conceptualization of disability. New accessibility solutions (e.g. self-service lifts) are part of



the outcome of this new paradigm of disability. Rather than special facilities, we are now seeing integrated facilities based on the new paradigm of accessibility. Solutions are no longer a response solely to technical requirements; they are also social solutions, addressing the issue of the place of the disabled in society.

Drawing on Becker's theory of the "the moral enterprise" (1985), I have reconstructed the normative process implemented by different stakeholders to impose their values and social rules on the rest of society. These stakeholders, whom Becker calls "moral entrepreneurs," are represented principally by one of the biggest associations of the disabled, the *Association des Paralysés de France* (APF). The Association has been a primary contact of the government and administrations when defining and implementing disability and accessibility policies since the mid-eighties. Other associations also play a role in matters of disability, but they have not tackled the issue of accessibility. APF feels public transportation accessibility is a collective problem that really needs to be remedied. Therefore since 1985, it has striven to have the issue addressed in a way that ties in with its worldview. This expression is used to refer to the concept of "paradigm" according to Kuhn (1973 & 1983). I have based my reasoning on this theory to demonstrate that APF has gradually succeeded in influencing the paradigm and the image of accessibility (and related solutions) stemming from the 1975 Act and, accordingly, the image of people with disabilities. My aim is to show how APF made sense of accessibility to others through utilizing several factors, including lobbying from the perspective of the disability paradigm. There has been a succession of paradigms during this period. For instance, criticisms of the solutions and results of the accessibility policy are just some of the resources that have been marshalled to challenge the balance of the policy and alter all the values, methods, and so on contained in it. By focusing the paradigm of disability on a social rather than an individual concept, the APF hopes to improve the acces-

sibility and the integration of disabled individuals into society. The final challenge goes beyond the issue of access to public transportation; it concerns the place of people with disabilities in our society.

Analysis of the solutions brings to light three major phases. Each phase is characterized by a dominant type of accessibility (the types of facilities selected or rejected and who they were aimed at) and by a discourse on disabled individuals. The first phase is defined as a phase of special accessibility. It began in 1975 with the publication of the Disabled Policy Act. The second period began in 1985. It was marked by the emergence of a new paradigm in the new transit networks and the persistence of old solutions. Above all, this was the point at which APF came onto the scene and began creating the paradigm of accessibility, supported by the evolution of the disability paradigm and general concerns about aging of the population. The new view began to spread. The last period, which began in 1996, saw integrated solutions becoming established and brought such a change in attitudes to accessibility that earlier facilities were no longer considered as factors enabling access. Consultation, which is now mandatory as part of urban transportation policies, has played a substantial role in developing accessibility.

### **1975 to 1985: Special Accessibility**

#### **Different Action for Different People**

The Disabled Policy Act came into force in 1975. The paradigm on which it was constructed consisted of a medical, individualized view of disability. It influenced the policy on accessibility to transportation that was slowly becoming established, such as policy agendas and publication of decrees in 1978 (decree of February 1<sup>st</sup> 1978 [n° 78-109] and decree of December 9<sup>th</sup> 1978 [n° 78-1167]). Based on the Act, a tendency emerged to classify people according to their impairments. Two sets of solutions for two distinct populations therefore characterize the first period (1975-1978). The first was for people in

wheelchairs, who were considered to be severely disabled, and the second was for all the others, the “mildly disabled,” who included those who were blind, deaf, and all others. This classification exists in Ministry of Transportation reports and in the White Paper setting out the policy of RATP in 1982 (p. 113). For the “mildly disabled” accessibility consisted of solutions integrated into transportation spaces. These solutions were assimilated into general policies on service improvement and improving comfort for all travelers. They consisted of the introduction of moving staircases, hazard warnings in the form of raised bumps along platforms (first tested in 1982, becoming generalized in their current form in 1987), and extra handrails in buses. For those in wheelchairs, accessibility involved special solutions, either in parallel (specialized transportation) or added to existing spaces, such as lifts alongside stairs.

### **Specialized Transportation**

Specialized transportation was viewed by the Ministry of Transportation and representatives of the transit companies (the Union des Transporteurs Publics (UTP) and the International Union of Public Transportation [UITP]) as the definitive solution for quality accessibility; for them it was not synonymous with exclusion or discrimination. It was even seen as a step forward, a response to the right to transportation for all. The first report by the Ministry of Transportation in 1977 even recommended that it should not be reserved solely for people in wheelchairs, but should be opened up to other sectors of the population who experience difficulties, for example elderly individuals or pregnant women. The Association des Paralysés de France (APF) was more ambivalent; its approach to accessibility developed over a number of years and it was only in 1989 that it began to consider specialized transportation officially to be complementary to accessibility to regular networks and not simply a palliative to the inaccessibility of public transportation.

### **No Action to Change the Environment (Spaces Or Equipment)**

Accessibility of regular services (buses, metro, trains) was planned, but the Ministry of Transportation and transit company representatives (the UTP and UITP) felt it was a less satisfactory solution than specialized transportation. Work to adapt the environment was not envisaged, as this extract from RATP’s policy shows. Wheelchair users, asking for highly integrated accessibility, were considered unrealistic: “This attitude shows a flight of fancy on the part of the individual; the disabled are entering the discourse from the standpoint of being equal to other people, and they are demanding that the world around them adapt to them (1982, p. 6).”

From then on, the solutions implemented consisted principally of technical features installed to overcome the inaccessibility of the space or equipment.

The French “bus of the future” project (1976-1980), the aim of which was to design a modern bus, was symbolic of the treatment of accessibility at the time. From the mid-seventies, urban transportation enjoyed a significant injection of resources (both human and financial) to cope with the challenges posed by the oil crisis and city centre congestion. It was in this context that the “bus of the future” project came into being. The specification set out points for improvement, namely safety, comfort, and accessibility. Accessibility was for the benefit of everyone except wheelchair users. It consisted of improving the way steps were arranged at entrances and exits, and ergonomic seating. Accessibility for wheelchair users, envisaged by one of the competing projects, was not selected. The various players in the public transportation arena, the state-owned vehicle manufacturer, Renault Véhicule Industriel (RVI), transit company representatives (UTP, of which RATP was a member) and the Ministry of Transportation opted for a bus with no sideways step or sloping floor within, and with a floor 560 mm above

ground level requiring two steps at the entrance and exit. This bus was in mass production from 1987, and was bought by most networks until 1995, when RVI began selling the first low-floor bus without steps at the entrance or exit, modeled on German buses available since 1987. Until 1985, accessibility policy was divided into two sets of solutions: facilities to make travel easier for the “mildly disabled” and special facilities for “disabled wheelchair users.”

### **1985 To 1996: The Emergence of a New Paradigm**

During the second period (1985-1996), new accessibility solutions on the new networks and on buses themselves began to appear, though the special facilities from the previous period still existed. However, there was no quick roll-out of accessibility, so APF set about structuring itself and its activity to modifying this situation.

#### **The Old Concept of Disability: Slowing Accessibility or Questioning the Benefit of Accessibility**

The large majority of accessibility solutions deployed (specialized transportation, chair lifts, disabled lifts) were typical of projects where accessibility is added as an afterthought rather than being integrated from the design stage and is intended for those identified medically as being disabled, that is, for one target population and only for that population.

This medical, individualized concept of disability had a number of implications. Firstly, it had been established that the number of people who could use the facilities was between 0.5% and 1% of the population, a tiny percentage of the mass population transit companies were hoping to attract. In light of this, the value of installing a lift was not particularly evident and had to compete with the installation of escalators that could carry a much larger constant flow. Secondly, the cost of these facilities seemed high for the tiny population they served, reducing still further the apparent benefit of developing accessibility. Transportation profession-

als often used this argument, as some of those spoken to, who were involved in accessibility policy, testify (Personal communication, three RATP’s managers 2003/09/16; 2004/02/04 and /16). Lastly, many in the transportation sector felt it was not really their responsibility. Because a “medical” approach was taken to the severely disabled, they felt a medical response would be more appropriate and that it was not their job as public transportation engineers to provide this. All these factors, which constituted the disability paradigm from 1975, masked the value of accessibility to the transportation sector and slowed the roll-out of accessibility.

This is apparent both from the comments of those working in the transportation sector, who all wanted to know how many people in wheelchairs would be using the facilities, and in the solutions deployed, as the following two examples illustrate. RATP policy during the 1980s did not include plans to make either old or new metro stations accessible to the disabled. In the old stations, many of which were built more than a century ago, with some dating from 1904, planned disabled facilities came up against administrative obstacles (protection of historic monuments), technical problems with the very dense subsoil of Paris (old quarries, many cellars, sewers, water, electricity and gas pipes), and the fact that there were few outlets at ground level (the average population density of Paris is 20,000 inhabitants per km<sup>2</sup> according to the last census, compared with 7,900 inhabitants per km<sup>2</sup> in New York). RATP, in its interpretation of the 1975 Act and associated decrees, saw rules on accessibility as applying only to new lines, so new stations built along extensions to existing lines were not designed to be accessible. This approach was sustained by the feeling it would be of little use to make only a few stations on a line accessible. Furthermore, a gap between the platform and train (consisting of an empty space and a step up) meant that accessibility was not assured.

## **New Dimensions to APF Policy: A New Approach to Disability and Integrated Accessibility Solutions**

An international debate on the concept of disability emerged during the 1980s, offering a new way of approaching disability from the point of view of the difficulties experienced by individuals instead of their impairments. This was a functional approach rather than a purely medical approach. This concept of disability and accessibility changed the boundaries of the disabled population, increasing the number of people who could be described as disabled and thereby increasing the benefit of developing access. Simultaneously, a new way of applying accessibility was being seen on new networks. It consisted of integrated accessibility planned from the outset and designed for everyone, enabling equal treatment through solutions that did not segregate.

In 1983, for the first time in France, a totally accessible network both in terms of its buildings and vehicles was opened (the VAL automatic metro in Lille). The accessibility provided by lifts and floor-level platforms fulfilled two conditions: It did not hinder operation and it provided equal access for all passengers. But for the majority of operators, these conditions could only be met on new lines, for example the tram systems in Grenoble (1987), Paris and Nantes (1982) and Rouen (1994).

Spurred on by the development of these solutions providing integrated accessibility for all, and given a renewed lease on life by the new representation of disability, APF mobilized to construct a policy aimed at promoting integrated accessibility by setting its rules (technical criteria), expressing its value (expansion of the population concerned), and participating in its application.

Becker's theory (1985) of the moral enterprise sheds light on APF's action. Becker discovered that stakeholders sometimes commit to introducing a new rule and that their actions can

be broken down into three stages, which are the stages I have defined above. The first consists of defining the rule from values. The second aims to attract the public's attention to the point they feel is a problem. Finally, the moral entrepreneur seeks to rectify the "social problem" through the application of its rule.

### **Stage One: APF Mobilizes to Act**

First, APF began by putting together its demands, by setting up a "national accessibility service" run by a paid worker. These demands, which were presented and approved at its 1983, 1985 and 1989 conferences, tell us much about APF's work to define its accessibility policy. In 1983, APF took its accessibility demands out of the social domain, and made them part of a drive for "Freedom of movement" under the law. In 1985, they were presented under a special heading: "Accessibility of private and public transportation."

At the same time, an operational approach was developing on the initiative of a few activists. It consisted of giving technical training to activists. The challenge was to enable these activists to become negotiators recognised by transportation and planning officials for their expertise in accessibility issues, with the intention of building bridges between the two worlds—the world of the disabled and that of the engineers. To spread this policy, which we will call "the professionalization of accessibility," more widely, the post of permanent technical adviser was created at the association's national headquarters. This structured approach is also evident in the position APF took as a result of its "entry on stage" (as defined by Becker, 1985) or the act that initiated APF's policy on transportation accessibility. In 1986, APF rejected an adaptation to the new R312 buses that came out of the "bus of the future" project because of its special, segregationist nature. The proposed solution was seen as an "*add-on*." This accessibility solution reflected the dominant view at the time; it was a chairlift at the rear door for use only by people in wheelchairs. Quite apart from the fact that the solu-

tion proposed by RVI was incompatible with operating constraints, such as stopping times or safety issues, it did not meet the accessibility criteria defended by the association, which was demanding accessibility for all, and above all, no special accessibility arrangements. APF posed as a transportation professional by taking operating constraints into account as a way of pressing its demands for non-segregationist solutions. It actively opposed the dominant approach to accessibility at the time. It sought to establish a different concept based on taking external factors into account, in accordance with the view that difficulties experienced by individuals arise from the interaction between individuals and society. From this standpoint, a person is disabled because of the obstacles in their path, which means-in political terms--ceasing to be concerned with access for everyone.

### **Stage Two: APF Expands the Affected Population to Increase the Perceived Benefit of Accessibility**

Becker identified two routes of action open to entrepreneurs for securing adoption of their norms. They are to ensure the support of other interested organizations, and to win over public opinion through the press and the other media: "If these efforts are successful, public opinion will take on board a specific problem and the competent organizations will act together to establish the desired rule" (1985, p. 161). This was the route taken by APF, and to attract attention it sought to enlarge the population affected by the problem to demonstrate the benefits of integrated facilities.

The idea was to link the demands of disabled people with broader concerns affecting a wider audience. To do this, it tried to compare the problems of individuals with disabilities with those of elderly people and parents pushing prams. For example, it produced a logo in the form of a frieze showing all categories of people who may experience problems traveling: in addition to people in wheelchairs, elderly individuals, adults with crutches, mothers

with prams, those who are blind, and children. It resorted to the abbreviation PMR (*Personne à mobilité réduite*, person with reduced mobility) and contributed to broadcasting this. But most of all, it took inspiration and a basis from the conceptual considerations of disability that came out of work to define classifications for disabilities led by Wood for the WHO (World Health Organization) (1980).

The categorization that existed during the first period gradually lost its strength, the boundaries of disability changed, and wheelchair users found new allies. This had a socio-economic impact, which changed the way the problem was tackled. Accessibility was no longer about accommodating a minority population, it was a policy to benefit a much larger group involving more people.

### **Stage Three: APF Participates Through the Professionalization of Activists and Consultation**

Third, APF became involved in rolling out this new accessibility rule. Many of the activities in existence before the service was set up in 1986 were resumed and structured. The service organized its policy along three principal axes: the first was to support the APF network by training local officers and providing materials and equipment (for communication, negotiation and information); the second was to raise awareness among the general public and those working in the sector, and the third was to maintain a dialogue with government and national authorities on the subject of accessibility. The focus was on taking accessibility out of the restrictive arena of disability and aligning it with wider issues, making it a collective action and a matter for everyone. To achieve this, APF centralized and professionalized the way its activists worked, tending to use official channels of consultation. APF carried out a number of high-level, centralized actions, such as lobbying and training at the Ministry of Transportation, among members of parliament, and the UTP. The public, extra-sectoral nature of decisions taken amplified the im-

pact of these. But it also pursued its activity at a much more decentralized level, in the approach and actions of its activists on the ground.

The Association's identity changed on three counts. Firstly, it moved away from the medical and social sector, entering new fields, like transportation and planning. Secondly, it gained the status of an expert in accessibility (it was already an expert in disability). Thirdly, it moved from being an opponent to being a partner. APF activists also had a change of image. Originally classed as workers in the social or charitable sector, they were increasingly viewed as professionals in accessibility, through the expertise they provided in working for a common cause—accessibility in cities for everyone. The work they did to publicise and secure the adoption of low-floor buses is a good illustration of this. In 1989, APF and the GIHP (*Groupement d'Insertion des Handicapés Physiques*, Physically Disabled Inclusion Group) organised a symposium in Dunkerque entitled, "Transporting Without Excluding." The two associations managed to bring together many professionals from the transportation sector to show them low-floor buses (with very low floors, almost to the ground, so no steps are needed at the entrance and exit) manufactured abroad. This communication initiative was a success, and fifteen years later those we spoke to still recall it (Personal Communication, RATP's managers or engineers, 2003 and 2004).

But the economic situation (the French jobs crisis) meant that transit companies continued to buy from the state-owned bus manufacturer, which until 1995 was still producing only R312 buses. The associations lobbied to try to get RVI to produce low-floor buses too, but it was the application of the Loi Sapin in 1993 that provoked a change in the situation, forcing companies to issue European calls for tender. Faced with competition, RVI modified its production and brought out a low-floor bus two years later. Sales of the previous model (the R312) collapsed in favour of the new buses. But there was little progress with the accessibility of bus services

for wheelchair users. The networks were mainly concerned with the absence of steps, making boarding and alighting easier for all passengers. Fold-out ramps enabling wheelchair users to board buses were available as an option that not everyone took. Buyers had taken on board the argument of making travel easier for everyone, but not that of including wheelchair users. Only a few networks tried to achieve full accessibility. The Etang de Berre network in the south of France was the first to do so. It would be used as a test and held up as an example for many years to come. Despite the European recommendations concerning accessibility on buses (COST 332, 1995), integrated accessibility was not yet seen as standard.

From 1985, APF spent their time on what tended to be official opportunities for consultation, which were used as a forum for discussing accessibility to spread the word. These included Departmental Safety and Accessibility Committees, to which plans for public buildings were submitted for approval, and Colitrah (Liaison Committee for Disabled Transportation), a consultation facility set up by the Ministry of Transportation following the 1975 Act. Many RATP and Ile de France regional officials attended and participated on a regular basis in the various meetings and working groups organized within this context. In this way, the association won members and even activists to defend and extend integrated accessibility. Furthermore, from 1990, they also had the chance to mix with researchers taking part in work on the International Classification of Impairments, Disabilities and Handicaps. The various participants uncovered conceptual thoughts on disability. By the early 1990s, the change in the way the population was perceived had passed into practice, as shown for example by a report by an official research body, the Institut d'Aménagement et d'Urbanisme de la Région d'Ile de France (IAURIF, the Ile de France Planning Institute, 1994), prepared by members of Colitrah. The report puts at 25% the proportion of the population affected by difficulties using transportation. The

concept of disability clearly falls into an environmental approach of situational disability. This information and the figure of 25% were regularly referred to by staff with responsibility for accessibility within their organizations (transit companies, research and consultative bodies, local authorities). They were in regular contact with the associations both through official structures and within their own companies as they monitored various projects. They usually adhered to the view defended by APF and played a part in disseminating a social view of disability within their organizations, even though they often met with rejection or reluctance on the part of other departments. So the ideas began to spread, but practical results had not yet been achieved, as the arrival of low-floor buses illustrates, in which full accessibility remained optional.

### **Initial Results**

These initial integrated facilities, available to everyone, illustrate the fact that the new paradigm of accessibility arising from an environmental view of disability was emerging and spreading. However, the previous representation of disability still persisted, expressed in tensions and resistance to attempts to make existing networks accessible. Stakeholders wanting to spread the integrated accessibility model stressed the benefits to the whole population of technical innovations (on metros, trams and buses) to such an extent that they were in danger of losing the specific issue of disability altogether behind more global concerns (aging, comfort). They evaluated experiences in France and abroad and were quick to draw negative comparisons, stigmatizing French “slowness” and pushing the French transportation sector to move in the required direction. Most of all, they played a part in policy development by becoming professionals capable of training and advising technical staff responsible for facilities, and combining to become partners to the key players in the transportation, planning and housing sectors.

The objective of APF activists in their action to improve accessibility was not only to provide current facilities but also to establish principles for future facilities. These principles were not merely technical standards. They also had an ethical and political dimension. They were at once a “moral” reference, a practical model and a “preparedness to act.” They constituted a constraining influence on all those involved in planning public facilities. By pushing the rules, the activists also sought to change social rules<sup>3</sup>, which define what constitutes “good” and “bad” facilities. This made them the ‘moral entrepreneurs’ described by Becker. He gives the following definition:

“Rules are the product of the initiative of certain individuals, and we can consider those taking this initiative as moral entrepreneurs. The prototype of the person who creates rules [but not the only type, as we will see], is the individual who undertakes a crusade to reform customs. He is concerned about the content of laws. Existing laws are unsatisfactory to him because one form or another of the evil, which he finds profoundly shocking, still persists. He believes that the world is not set right until rules have been introduced to rectify this” (1985, p. 171).

### **Post 1996: New Integrated Solutions Become the Rule**

During the second period, the paradigm conveyed by APF and a number of other agencies had spread, and from 1996, accessibility guided by this new paradigm was in its implementation phase. The third period was characterized by the large-scale application of integrated accessibility, despite the fact that a few traces of old attitudes remained. However, the associations continued to demand even greater equality of treatment.

### **Integrated Accessibility Facilitated by Systematic Consultation**

From 1994, when the first French low-floor buses (GX317) came onto the market, more and

more networks were buying low-floor buses. This continued the following year when the Agora, RVI's accessible bus, came onto the market contributing to the collapse and end of sales of the R312. At the same time, transit companies were finding low-level floors still did not meet the accessibility needs of wheelchair users, that it was important for the optional fold-out ramps to be added, and that bus stops also needed to be adapted. In 1998, RATP decided to include the ramps in all their specifications for new buses; they also wrote a guide to making transportation accessible and drew up bus stop adaptation procedures in association with local authorities responsible for highways. So as not to discourage the bus companies, a representative of APF explained the gradual nature of the demands: "You already have low-floor buses; now we can talk about accessibility" (Personal communication, APF manager 2004/04/23).

The dialogue was facilitated by the publication in 1996 of LAURE (*Loi sur l'Air et l'Utilisation Rationnelle de l'Energie*, the Air and Rational Use of Energy Act), which made it compulsory for major metropolitan areas to prepare Urban Transit Plans (PDUs), extending the transportation theme to cover all routes and introducing local consultation procedures. An evaluation by CERTU (2002) shows that consultation took on different forms in different metropolitan areas, from information alone to the joint planning of projects. Institutionally, it had been fairly major (partnerships between those involved in the transportation sector, but also with local councils and socio-economic players) as far as dialogue with the population was concerned, and it had been conducted in an exhaustive manner, with focus on the associations rather than with the population as a whole (compulsory public surveys, neighbourhood meetings, working committees, information displays). In 2000, the Solidarity and Urban Renewal Act (SRU) on town planning revived the process. Activists from the departmental branches of APF became involved in these new forums for dialogue. Generally, they already

knew some of their interlocutors from having worked with them on the departmental safety and accessibility committees. The work carried out within these consultation groups gave impetus to the total accessibility approach to cities, covering highways, buildings, transportation, shops. The example of the Ile de France PDU is a good illustration. For each bus route selected in the PDU, regular meetings were held with, among others, representatives from APF. At the same time, the city of Paris had set up working groups for each disability, which included representatives from associations, to prepare planning guidelines for traffic areas, to become applicable in 2002. RATP did the same, introducing a consultation group in 2001 that included representatives of associations to advise on and test the company's various accessibility projects. Participants in these forums for dialogue and exchange were now thinking in terms of "architectural obstacles." Accommodating accessibility was a positive experience, as many of the comments gathered show: "It's useful," "We're fulfilling our public service remit," "It's natural"... (Personal communication, Poitiers's and RAPT's engineers, managers and politics, 2003-2004).

Some engineers were not slow to use accessibility arguments to get plans passed by local residents. Associations saw the value of getting organized and grouping together to improve their effectiveness in local negotiations by having clear, shared objectives. In the Ile de France region, APF created the post of regional coordinator, a single point of contact for regional companies such as SNCF and RATP (instead of having one contact per department). Elsewhere, some associations got together in departmental or regional collectives, on APF's initiative, to promote accessibility. So, buoyed by consultation, the tendency was for integrated accessibility designed for everyone on all modes of transportation (bus, rail and tram) to become generalized. Yet a few traces of the old paradigm persisted, evident in hesitancy or reluctance to act.



## Traces of the Old Paradigm Persist

Despite the deployment of the new type of accessibility, several examples illustrate the persistence of the old view of disability. The first is provided by the models of lift installed during the 1990s by RATP. These were self-service lifts, but they were designed for moderate use (only by wheelchair users) and proved to be under-dimensioned for the large number of people actually using them. The second concerns the type of audible announcements to be given on Metro platforms. Until the middle of 2004, RATP's "accessibility" and "Metro" departments were hesitating between on-demand and automatic announcements, opting finally for the latter because on-demand announcements would have meant some effort on the part of the staff concerned (with information) to reach a box to trigger the announcement. The restriction on the use of equipment is another example of the persistence of the old view. Bus ramps are still reserved only for wheelchair users; they are not used for pushchairs, which have to go through the front door to validate their ticket. Limitation of the use of wider motorized gates on ticket control lines at stations was also under discussion until 2004. RATP feared these facilities could be "dens of fraud," enabling several people to go through at once. It wanted to limit their use only to those requesting it in advance, but this came up against a number of operational problems (what do people changing trains do?) and opposition from APF.

The new paradigm guiding accessibility (and related solutions) is based on first equipment attempts stemming from the 1975 Act. IT is gradually replacing it as individuals slowly assimilate information about the situation and the resources they have to deal with it. This explains how accessibility policy has shifted, changed at the edges in accordance with Charles Lindblom's theory (1959) and Brian Quinn's work on incrementalism (1980). Accessibility policy continues to evolve, as do APF's demands.

## Increasing Demands

As accessibility evolves on many bus and metro services, APF is also evolving its demands. It is now asking for high quality integrated accessibility, judged on the basis of the availability and reliability of facilities, and for this to cover all travel. But networks are still not capable of providing a quality service, either because of financial problems (under-dimensioned lifts that still have some years of service to go, vehicle fleet costs to recoup), or because of technical problems, particularly on old networks. These problems did not escape the notice of representatives in the Senate in October 2004, who refused to set a date by which all public buildings had to comply with accessibility standards. In the end, the final version of the Act passed on 18 January 2005 gives a 10-year deadline with the potential for exceptions to be made in exceptional circumstances.

But the moral entrepreneurs are continuing their efforts to influence the paradigm by approaching it from the point of view of human rights and non-discrimination. The mismatch in the concepts of accessibility held by the different stakeholders (transit companies and associations) is apparent from their annual reports. For example, when RATP's accessibility task force gave a figure for the number of accessible bus services it runs, APF's Paris branch found far fewer and the Association's headquarters asserted that there were none at all. For RATP, accessibility is limited to what falls within the scope of its responsibility, that is, equipping the service with ramped buses and adapting bus stops in association with the agencies responsible for highways (local councils, departments and central government). The departmental branch of APF takes account of facilities over a much wider radius (routes) and in particular evaluates the way accessibility works (whether the person can use the bus). The accessibility department at APF's headquarters believes that accessibility will only truly exist when wheelchair users can use buses under exactly the same conditions as

the able-bodied. This has led to demands for the space reserved within the bus to be doubled and for access through the front door like all other passengers (a frequent operating condition on networks including that of RATP). For them, accessibility is not about whether someone can make a journey (fairness) but about how they can do it (equality). The right to travel can therefore mean different things to different people.

In the 1970s, the Socialist Party saw fairness as the provision of transportation for everyone (using different solutions, school buses, scheduled services or minibuses). Nowadays, APF sees fairness as equal treatment, the same service for everyone, as if differences did not exist. One representative of APF stated: “We do not want to be different from other people; we want to be offered the same service as everyone. Integration is about having the same type of service as that given to the able-bodied” (Personal communication, local APF managers, 2003/04/23). An appropriate way of expressing this would be, “We are all the same.”

### Conclusion

Accessibility in France is now designed and planned from an environmental standpoint despite still overt reluctance. This way of tackling the issue has become the only way of approaching it for all stakeholders. It has become a social rule, in the sense that Becker was referring to when he wrote, “Social rules define situations and the types of behaviour appropriate to them: some actions are prescribed (what is ‘good’) and others are prohibited (what is ‘bad’)” (1985, p. 25). Accessibility, as defined following APF’s action, has a philosophical, and ethical dimension. It is a moral reference and a practical model translating into integrated solutions. The study of the paradigm of public policy “makes it possible to account for an ongoing reinterpretation of the world, influencing political rhetoric and reconstructing institutional standards” (Jobert, 1995, pp. 23-24). Influencing the disability

paradigm and creating the accessibility paradigm was not devoid of tension and did not occur overnight. Changes have been slow and are yet incomplete. The associations of the disabled are the stakeholders promoting the move to an environmental approach. APF is undertaking a moral enterprise, as defined by Becker. It is imposing a new perception grid of reality. The changes over thirty years have translated into facilities that have been designed differently in the field. At the beginning, the facilities were more specialized and specific to target publics whereas for the past few years they tend to be integrated into the space and available to all. The accessibility to the public transportation networks is now seen as indispensable and complementary to special transportation solutions. Other facts testify to the State’s vindication of the moral enterprise, as can be seen in the publication of various laws promoting accessibility for instance. APF is committed to legislative work to ensure that its outlook prevails even if it is not entirely successful each time, as can be seen in the latest draft of the amended law of 1975, of January 18, 2005 that still states that special transportation is a remedy to the inaccessibility of public transportation. However, APF demands continue to move toward a demand for greater quality and, above all, equality between those considered able and those considered disabled.

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## Glossary

- APF: Association des Paralysés de France  
CAP: Poitiers Metropolitan area  
CERTU: transportation and planning study and research centre  
CIH: International Classification of Impairments, Disabilities and Handicaps (ICIDH)  
Colitrah: Liaison Committee for Disabled Transportation (forerunner of Coliac)  
Coliac: Liaison Committee for Accessibility (replacing Colitrah)  
GIHP: Physically Disabled Inclusion Group  
LAURE: Air and Rational Use of Energy Act

WHO: World Health Organization  
PDU: Urban Transit Plan  
PMR: Person with reduced mobility  
RATP: Régie Autonome des Transports  
Parisiens  
RVI: Renault Véhicule Industriel  
STP: Société des Transports Poitevins  
UITP: International Union of Public  
Transportation  
UTP: Union des Transporteurs Publics

### Resources

Access Able Travel Source, [www.access-able.com](http://www.access-able.com)  
Accessible San Diego, [www.accessandiego.org](http://www.accessandiego.org)  
Adaptive Environments, [www.adaptenv.org](http://www.adaptenv.org)  
APRODDIS--Asociación Pro Desarrollo de la Persona con Discapacidad, [www.aproddis.org](http://www.aproddis.org)  
Apumayo Expediciones, [www.apumayo.com](http://www.apumayo.com)  
Argentina Tourism for All Foundation, [www.turismoparatodos.org.ar](http://www.turismoparatodos.org.ar)  
Chalfont Lines, [www.chalfont-line.co.uk](http://www.chalfont-line.co.uk)  
Dubai Department of Tourism and Commerce Marketing, [www.dubaitourism.co.ae](http://www.dubaitourism.co.ae)  
Epic Enabled, [www.epic-enabled.com](http://www.epic-enabled.com)  
Flying Wheels Travel, [www.flyingwheelstravel.com](http://www.flyingwheelstravel.com)  
Government of Canada "Persons with Disabilities Online," [www.pwd-online.ca](http://www.pwd-online.ca)  
The Guided Tour, [www.guidedtours.com](http://www.guidedtours.com)  
Ibero-American Congress on Tourism for People with Disabilities: Consumer Market for Tourism without Barriers, [www.turismosembarreiras.com.br](http://www.turismosembarreiras.com.br)  
Independent Living Institute, [www.independentliving.org](http://www.independentliving.org)  
International Air Transport Association, [www.iata.org](http://www.iata.org)  
Kéroul, [www.keroul.qc.ca](http://www.keroul.qc.ca)  
MIUSA-Mobility International USA, [www.miusa.org](http://www.miusa.org)  
National Centre for Promotion of Employment of Disabled Persons, [www.ncpedp.org](http://www.ncpedp.org)  
Nautilus Tours & Cruises Ltd., [www.nautilustours.com](http://www.nautilustours.com)  
Nuevo Mundo Viajes, [www.gruponuevomundo.com.pe](http://www.gruponuevomundo.com.pe)

Open Doors Organization, [www.opendoorsnfp.org](http://www.opendoorsnfp.org)  
Paralyzed Veterans of America, [www.pva.org](http://www.pva.org)  
PromPerú, [www.peruonline.net](http://www.peruonline.net)  
RADAR—Royal Association for Disability and Rehabilitation, [www.radar.org.uk](http://www.radar.org.uk)  
SATH—Society for Accessible Travel & Hospitality, [www.sath.org](http://www.sath.org)  
Sundial Special Vacations, [www.sundialtour.com](http://www.sundialtour.com)  
Tourism for All UK, [www.tourismforall.org.uk](http://www.tourismforall.org.uk)  
US Access Board, [www.access-board.gov](http://www.access-board.gov)  
US Department of Justice "ADA Home Page", [www.ada.gov](http://www.ada.gov)  
Wilderness Inquiry, [www.wildernessinquiry.org](http://www.wildernessinquiry.org)  
World Tourism Organization, [www.world-tourism.org](http://www.world-tourism.org)

### (Endnotes)

<sup>1</sup> This thesis research occurred with participative observation over a period of 3 years at the Accessibility Department of RATP. The research was supported by more than sixty confidential interviews with people involved in accessibility (for example, employees of public transportation companies and urban communities, associations, ministers and consultants) and by reading academic and specialized magazines, such as RATP magazines and those of APF and the city of Poitiers.

<sup>2</sup> Until the late eighties, the French State had representatives on the RATP Board of Directors.

## **Ethnobotany on a Roll! Access to Vietnam**

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**Abstract:** This article describes the research and experiences of an ethnobotanist with a physical disability working in Vietnam. Due to a spinal cord injury, the ethnobotanist uses a wheelchair and walking canes to explore the bustling food markets of Vietnam. Information and recommendations are provided for equipment and traveling to and in Vietnam, particularly for those interested in conducting scientific research and for travelers with physical disabilities. Success is largely due to the mutual respect and kindness shared by people along the way, and by accepting and accommodating to given situations. Appendices of resources for travel in Vietnam and educational granting sources for people with disabilities provided.

**Key Words:** Vietnam, travel, ethnobotany

### **Introduction**

Conducting field research requires tremendous planning and organization. One must plan ones research agenda and schedule, obtain research permits, and if the research is to be carried out in a foreign country, establish contacts or collaborations and apply for the necessary visas. When the paperwork is finished, one needs to consider and pack field equipment and supplies. Finally, there are the mundane personal requirements of lodging, food, and clothes. For the researcher with physical disabilities, the tasks and supplies previously described are only the beginning of a myriad of other logistics to be worked out.

I am an ethnobotanist. Ethnobotany is the scientific study of dynamic relationships and interactions between cultures and their botanical

resources. I am also an “incomplete-quadruple-gic.” This means that in addition to packing my plant press and clippers, I also pack tools to fix my wheelchair, my canes, and enough anti-spasmodic medication to last the entire research period abroad.

The invitation to write this report was by the Center for Southeast Asian Studies at the University of Hawai'i at Mānoa (an earlier version of this report is available through their online archives). Their intent is to attract a broad range of scholars to the study of Southeast Asia by increasing awareness of the field to all, especially under-represented groups in the field. People from different backgrounds enrich the field by bringing to it their unique perspectives and strengths. In this printing of the report, I encourage those working in disability culture to consider Vietnam (Việt Nam) as a future research site. There are opportunities for studying a disability culture that is shaped by the past circumstances and new opportunities of an incredibly fast-developing country.

The following report describes my experiences traveling and conducting research in Vietnam from November 2003 through March 2004<sup>1</sup> specifically as a person with a physical disability. I provide a range of information, from general travel (e.g., visas and transportation options) to specifics regarding scientific work in Vietnam. Although the information is from the perspective of work in Vietnam, I am hopeful that it may serve as well to assist those considering fieldwork in other Southeast Asian countries or anywhere in the world, with or without disabilities.

### **Establishing Foreign Country Contact, Collaborations and Visas**

My research involves the ethnobotany of Vietnamese people in Vietnam and diasporic Vietnamese groups abroad. In the U.S., much of my research has involved Vietnamese immigrants in Honolulu, Hawai'i. In Hawai'i, field research consists of going to peoples' homes to

conduct interviews or participate in community cultural events and make botanical collections from the Chinatown markets. I have a vehicle that allows me to be independent and very mobile. When I have finished a day of collecting or interviews, I bring the specimens back to the lab to prepare them for drying in a plant press, or go to the computer to enter new ethnographic data. The building where the lab is located is wheelchair accessible, equipped with an elevator, and I have my prepared lab space. While working in Hawai'i, perhaps the main logistical problem for me to consider is finding a parking space where I can easily and safely pull my wheelchair in and out of my van.

Working in the U.S., and practically in my own back yard, I do not have to search out collaborations or obtain visas. In contrast, Vietnam is a country where contacts are very important. Additionally, following the ethical standards in ethnobiology<sup>2</sup> and CITES (the Convention on International Trade in Endangered Species of Wild Fauna and Flora)<sup>3</sup>, one must establish host country collaborators and obtain the appropriate visas and necessary permits. I was very fortunate to be introduced to Dr. Jack Regalado, a scientist from the Missouri Botanical Garden (MBG) working in Vietnam. MBG, along with the Institute for Ecology and Biological Resources (IEBR) of the National Center for Natural Science and Technology (NCST) in Hà Nội (Hanoi), Vietnam, collaborate on the Vietnam Botanical Conservation Program (VBCP). Upon contacting Dr. Regalado, I was directed to send my request of research dates, my curriculum vita and passport information so that IEBR could begin my application for a research visa.

Once IEBR completed the visa request in Vietnam, they faxed that request to the Vietnamese Embassy in Washington, D.C. IEBR provided the Vietnamese Embassy with the official "invitation" and proof that I had formally established contact with them, but I still needed to apply for a visa through the ordinary visa application process. This application can be ob-

tained through the Internet World-Wide-Web-site of the Vietnamese Embassy. As a visiting scientist, I was directed to apply for a business visa. Under these conditions, my request for a six-month visa was granted. Otherwise, as a foreigner with a tourist visa, one would receive only a one-month visa, and as a Vietnamese-born person living abroad, one could obtain the maximum of a three-month tourist visa.

### **Things to Consider Before Going to Vietnam...**

...Or anywhere else in the world traveling as a person that uses a wheelchair or that has a mobility impairment.

**Wheelchair** - I highly recommend a lightweight, FOLDING chair. While many wheelers now use the "rigid" frame chairs (only the back folds down to the seat), you will gain access to many more places with a folding chair because it can fold narrower. A folding chair is also easier to store away on small rickshaws and various watercraft.

**Wheelchair tires** - Go Solid – no flats. I am not talking about the heavy inserts that go into an outer wheel. Rather complete solid tires that fit onto the wheel rims (e.g., Mako® brand tires). I began using solid tires in 1992 when I was living in Paris. Considering all the many curbs over which I had to hop up and down, my solid tires held up stupendously and I never had to worry about low air tires or flats slowing me down. Solid tires are available through wheelchair supply companies; both can be found through an Internet search.

**Tools for fixing your chair** - Bicycles are a main form of transportation in Vietnam, therefore it is possible to find a bike mechanic to fix your wheels. However, I recommend becoming self-sufficient with general cleaning of the tires and brakes to keep you rolling and doing research.

**Wheelchair gloves** - Bring extra pairs. Wheeling down the streets, through markets, and back

hamlet passages of Vietnam, you want to protect your hands, just like rolling in the U.S. My work in the markets finds me rolling through everything from the juices of fruits to fish, gasoline, potted asphalt, and mud. Gloves provide protection and cleanliness. I use weight lifting gloves instead of bicycling or “wheelchair” push-gloves. Weight lifting gloves can be found in general sporting goods stores and should be made of durable leather, with a double-layer in the palm area.

**Canes** - I use a wheelchair, but I am able to walk slowly. Using collapsible hiking canes provided access to places a wheelchair did not fit. I traveled with my canes collapsed and tucked on the side of the chair. Leki ® makes telescoping walking canes that are strong and light. I have been using this type of cane since 1998 and find them safer, more efficient and versatile than the elastic cord folding canes sold by medical supply companies.

**Large bag** - A bag that can hang from your wheelchair is better than a backpack. I use a large canvas bag that hangs from the push handles of my wheelchair. This type of bag allows me to collect many specimens from the markets and carry them without them being crushed inside a zipped-up backpack. Some people are concerned that the bag might get stolen or people will steal items out of the bag from behind without my knowing. Looping the bag straps a couple of times around the handles of the wheelchair will keep it secure. As for having items taken out of the bag, this is not something I worried about and my vegetables always came home safely.

**Personal care needs** - While there are many people with disabilities in Vietnam, my experience is that they have adjusted to their abilities with whatever local resources are available, just as we do in the U.S. – except that they are tougher! Consider your personal care needs, but have an open mind and be willing to adjust, have less, and do things differently.

**Bathrooms** - Accessible bathrooms – forget about it. All right, there are accessible toilets in newer buildings, for example the public library in Biên Hoà, and the Hà Nội-Nôi Bài (Hanoi Noibai) Airport. In most cases, however, the toilet facilities, often labeled “WC” (short for Water Closet), are up a few steps, and, if you can squeeze through the doorway, are in the style of squat toilets (similar to a urinal, but on the floor). Even if you are lucky enough to find a sitting toilet (usually more modern public facilities or modern private homes) the doorways are too narrow for a wheelchair to enter. Be prepared – carry provisions, be creative, wear pads, ask a friend to shelter you while you do your business. While living in more rural areas, at “*nhà quê*” or countryside homes, where most homes have only squat-toilets that are usually located away from the house, I fashioned a chair that could be used as a toilet. The “toilet chair” was made from a plastic 4-leg stool with a large hole cut out of the seat into which a plastic “potty” could be placed. It was very light, easily transportable, and could be placed wherever was most accessible (and appropriate!) for me to use. The “potty” bowl could also be lined with a disposable plastic bag or just washed out.

**Medications** - If you take medication daily, calculate what you will need, then bring extra in the event that you remain in the country longer than expected. Pack them separately just in case you lose your luggage. My health insurance company had procedures for medical care outside of the U.S. Research what is required and follow the procedures to ensure you will be covered. There are many therapies in Eastern medicine that I have been offered to alleviate my “condition.” There is no doubt that you will encounter the same; exercise caution and use commonsense.

**Last word** - Even the most “physically functional” researcher encounters discomforts in the field. It is often about how far out of your “comfort zone” you are willing to go, not about what you are able to do. Cliché it may be, but

“where there is a will, there is a way” still holds. Actually, being away from the amenities of the First World can be quite liberating and you may be happily surprised with what you learn about yourself.

As John Hockenberry, former NPR correspondent and wheelchair user told me, “There’s no reason to stay home.”

### **Getting to Vietnam - Airplane Travel**

I make my flight reservations for Vietnam through Pacific Ocean Travel, Inc. (808-522-0990). Pacific Ocean Travel is a Honolulu-based travel agency that specializes in travel to Vietnam and other Southeast Asian countries. They can also do the paperwork for a “tourist visa.” However, as I described earlier, one should determine what type of visa they will be traveling with, tourist or business.

I usually inform the airline company at the time I purchase the ticket that I use a wheelchair. Airports and airplane personnel are prepared for wheelchair users. When traveling from the Honolulu Airport to Vietnam, for example, airport attendants will assist wheelchair users to get to the gate and even handle your carry-on luggage. Interestingly, I think that most people who use wheelchairs and travel by airplane are those that have a disability due to their advanced age. They often use the airport wheelchair, and then appear very dependent on the assistance of others. By contrast, younger people with a disability travel with their personally owned chair and are very independent. This is based on my observations and interactions with the “wheelchair” attendants at airports, who always want to push my chair for me because they are not accustomed to my independence.

On the positive side of all this attention, having an attendant escort you to the gate can save you much time by passing long security check lines – I am usually wheeled right up to the front of the line (the attendant doesn’t have

time to wait either!). In many older airports, the main route to and from boarding gates is non-accessible and the alternate routes require you to go through locked doors, freight elevators, or back corridors. This is where an escort by the airport attendant is essential. My advice: sit back (or politely and patiently state that you would rather push yourself) and enjoy the ride through the security checkpoints and other “authorized personnel only” access ways. You will get to your plane on time.

Earlier, I briefly mentioned the need to pack medication and additional tools for ones wheelchair. This packing of the “extra” personal necessities is an important point to remember due to weight restrictions for luggage on planes. Equipment and supplies needed for fieldwork and books are heavy. On one occasion when I arrived at the Honolulu airport, one of my bags was overweight. Fortunately, I had grams to spare in the other bag and could transfer items. This is when it occurred to me that a large part of what I needed to pack was related to my spinal cord injury and included items a fully ambulatory researcher probably would not pack. Ideally, the person with these needs would be allowed a certain weight exemption that is not counted as luggage, as in the case with personal wheelchairs.

The Taipei International Airport, in Taiwan, and the Hà Nội-Nội Bài Airport have wheelchair accessible restrooms. I am uncertain about the international airport outside of Hồ Chí Minh City (HCMC). When flying domestically, the airport near HCMC has an accessible bathroom, but it is on the second floor and I was told there is no elevator.

At the time of this report, the flight between Honolulu, Hawai‘i and Hà Nội, or HCMC, Vietnam requires an overnight stop in Taipei, Taiwan. This is referred to as a “transit.” If one flies on China Airlines, there is no extra charge for the shuttle bus, meal, or overnight stay at the Airport Hotel. The shuttle bus is not wheel-



chair accessible. I could walk onto the bus. I was told that someone who could not walk would be carried on. Likewise, the Airport Hotel does not have official wheelchair accessible rooms, although the entrance into the hotel is ramped. However, unless ones wheelchair is very narrow, it will not fit into the bathrooms, and one will also have to accommodate to the high-walled bathtub. Fortunately, it is only for one night.

One last piece of advice regarding stopovers and wheelchairs: Unless it is only a one-hour stop, never agree to have your wheelchair checked all the way through to your destination. I agreed to this once during my international travels and my wheelchair was lost to another plane when mine was rescheduled due to bad weather. You need to be comfortable and independent, especially when you are faced with uncertainty about accessibility. Airport wheelchairs are over-sized and difficult to maneuver when you are accustomed to pushing around a 14-inch lightweight wheelchair. Additionally, personal wheelchairs are hot-ticket items in the developing world where there are people with physical disabilities limited to ground level-wheeled carts for mobility.

### **In Vietnam**

At the time of my most recent visit to Vietnam last year, the country was in preparation for hosting the upcoming SEA Games (South-east Asian countries sports competition), followed by the ParaAsean Games. Due to these events, Vietnam was in a frenzy of infrastructure improvement (e.g., roads, sidewalks, ramped curbs, especially in tourist areas). Unlike the poorly broadcasted Para-Olympics by the U.S., the ParaAsean games were well televised and celebrated in Vietnam. Vietnam and other South-east Asian countries are very interested in improving conditions for people with disabilities. The coincidence of the timing of events and my being a wheelchair user added another interesting perspective to my research. My reception as a person that uses a wheelchair was different

from my first visit to Vietnam in 2000. First, many people thought I was a wheelchair athlete taking part in the games. Second, people were much more aware of the great athletic abilities of their fellow Vietnamese with disabilities. Both of these contributed to my feeling a higher level of respect and recognition. I believe the ParaAsean games were important in helping to change popular conceptions of those with disabilities.

### **Contact Period in Hà Nội**

The main purpose for my entry into and exit from Hà Nội was to formally meet and thank the collaborating scientists at the Institute for Ecology and Biological Resources (IEBR). The IEBR building is located on the campus of the Vietnam National Center for Science and Technology. There are 3 to 4 steps into the IEBR building and there is no ramp. I walked up the steps using my canes while my wheelchair was carried up. The building is equipped with an elevator. There are restrooms with sit-down toilets, but the entrance into these is too narrow for a wheelchair to enter.

While in Hà Nội, I stayed at the Missouri Botanical Garden's (MBG) house. This is the residence of Dr. Regalado, the MBG scientist working with IEBR. Guests of MBG or the Vietnam Botanical Conservation Program (VBCP) often stay at the house while working in Hà Nội. This turned out to be an ideal situation because the house has a guest room and bathroom on the first floor. There are a couple of steps to get into the house. I believe that if I were unable to walk, Dr. Regalado would have worked out access. Please see the end of this report for information on commercial accommodations in Hà Nội and of Hồ Chí Minh City.

The MBG house is located near a market; making it convenient for breakfast, shopping, and an initial look at the markets of Vietnam. Both the MBG house and the market are located on Linh Lang Street; where there are either no sidewalks or they are very narrow. I wheeled

in the street, however, relatively safely, as this is not a main traffic road and is in good condition. Shopping at the street market is very accessible. Vendors lay out their food items at ground level, so all the fruits, vegetables, leafy greens, fish, clams, flowers, herbs, etc. are visible. Under the covered market area where prepared foods are sold (i.e. soup and noodle vendors), the paths are wide enough for a wheelchair.

### Research Period in Biên Hoà

Biên Hoà City is located in Đông Nai Province in southern Vietnam. It is approximately 30 km northeast of HCMC, making it a convenient location to do research in an average size city with less tourist influence, but with relatively easy to access larger institutions in HCMC.

Biên Hoà is also my place of birth. Most of my extended family who lived in Biên Hoà immigrated to the U.S. between 1973 and 1990. I left in May, 1975. Currently, only my eldest aunt, her husband, grown children and their families live in Biên Hoà. During most of my four months in Vietnam, I lived with my aunt in her newly built house. It is not wheelchair accessible, but accommodation could have easily been made if I was completely non-ambulatory.

The Biên Hoà district, like much of Vietnam is developing quickly. Everywhere one sees new infrastructure (e.g., new, larger water pipes, street widening). This in turn leads to the demolition of old houses and the building of new, taller ones, as well as new shops, dance clubs, and cafes. All this demolition and building also means that many sidewalks are crumbled or completely impassible. Where the sidewalks are new or intact, they are often used as parking areas for motorbikes, and therefore still impassible. When I used my wheelchair, I usually traveled in the street. Wheeling in the road was often dusty and noisy but commuters were generally very aware of their surroundings and I never had an accident.

### Research and Transportation

My two market research sites consisted of a small, neighborhood market close to my home and the large Biên Hoà market farther away. I went to the small market using my wheelchair, hugging the side of the road. There are newer sidewalks at the market but vendors use these areas to display and sell their products, so I found myself out on the street anyway. The covered area of the market has narrow passageways of bare-packed dirt that are quite pitted and muddy from rain and other liquids. I could still enter them, much to the chagrin of other shoppers vying for the same space as they squeezed past with their bicycles and motorbikes. Similar conditions are found at the larger Biên Hoà market, but the passageways are generally paved, though this does not mean they are smooth!

Going to the larger and more distant Biên Hoà market required my hiring transportation. This was in the form of a “*Xích-lô*” (pedicab) or a “*Xe-ôm*” (motorbike taxi). I hired *Xích-lô*s when I needed to have my wheelchair with me. I would fold up my chair and climb into the seat, and then the chair would be placed in the front area of the *Xích-lô* where I placed my feet. After some experience, I knew how to secure and hold the chair so that it was not too uncomfortable. The convenience of being able to fold the chair in this situation is one of the reasons I recommend the folding style wheelchair. *Xích-lô*s are the cheapest form of hired transport, usually a few thousand Vietnam Đồng (VNĐ) per kilometer. The price is always negotiated, with the foreigner usually paying more than the local person. They are also very popular with shoppers because it is possible to transport not only the shopper back home, but also many bags of food items. For this reason, *Xích-lô*s are often found in convenient locations at markets ready to peddle a shopper home. An added positive note is the fact that because they are pedaled the ride is slow and leisurely, allowing for sightseeing. Although I climbed into the *Xích-lô*, I think they could still be accessible if the passenger was

not ambulatory. The pedaler lifts the back of the *Xích-lô* so the seat is low in the front to allow the passenger to climb in. If one is adept at wheelchair transfers, it would be possible to transfer into the *Xích-lô* seat. If one is of small stature, there may be an offer to lift one into the *Xích-lô*, as I sometimes experienced.

When I did not need to bring my wheelchair, my preferred transportation was by a *Xe-ôm*. These are men on motorbikes whom you hire for rides. The term *Xe-ôm* literally means “hugging vehicle.” These are a little more expensive than the *Xích-lô*, but considerably faster (and potentially more dangerous). They too establish a regular waiting area where their customers can find them.

If you need regularly scheduled transportation, you can arrange scheduled pick-ups with one *Xe-ôm* driver. However, only pay per ride. I had a regular driver who picked me up three times a week to go to a local pool. Of course, both a *Xích-lô* and a *Xe-ôm* can be waved down for hire; sometimes they solicit you if you look as though you need a ride.

Taxis or a car with a driver are better for further distances. Both taxi and car hire companies can be located by calling directory assistance, and taxis often congregate at strategic locations (near tourist areas, museums, bus stations). I used taxis when I needed to travel with my wheelchair beyond Biên Hoà City. Depending on the distance or duration of the trip (i.e. numerous days to different provinces), car hire is the better option. When I traveled into HCMC from Biên Hoà (+ 60 km round trip), it was cheaper to hire a driver for the entire day. One trip I made to HCMC, leaving Biên Hoà in the early morning and returning in the evening cost 350,000 VNĐ, about \$23.00 US.

Buses are also available. In contrast to the price for car hire to HCMC, a one-way bus ticket between the two cities cost 20,000 VNĐ! Local city buses are not available everywhere; for example, there is no local city bus service in Biên

Hoà. In Hà Nội, and I am told in HCMC, there are city buses, but they are not wheelchair accessible. When I lived in Paris, I would routinely take the non-accessible buses, folding my chair, and pulling it up the bus steps. From what I observed in Hà Nội, this is not as easy in Vietnam. I once considered taking the bus in Hà Nội. I sought out a bus stop but its placement and design made it impossible for me to wait in front. When the bus arrived, the mass of motorbikes in the street kept the bus from stopping near the curb. People descended and boarded the bus through the maze of motorbikes. I waved down a taxi instead.

Other forms of vehicle transportation available in Vietnam include multi-passenger vans and longer-distance buses. The vans travel longer distances, picking up additional passengers along the way. While these are cheaper, if one can afford the price, I feel that hiring a car and driver is the best option for research travel purposes. For my own work, the greatest advantage to having my own car and driver is the option of stopping wherever there is something of interest to photograph, research further, or just to relieve myself.

Unfortunately, I did not have the opportunity to travel by train – next trip. From my inquiry on the Internet, the trains do not appear to be accessible. Airplane flights are available between many larger cities in Vietnam. My flights between HCMC and Hà Nội cost on average 1,450,000 VNĐ or \$100.00 US.

An added interesting note regarding motorbikes: there are three-wheeled motorbikes available. Vietnam has many people who are physically disabled due to war-injuries, polio, birth defects, etc. Since the most common, and cultural form of transportation is by motorbike, many people have modified motorbikes with two wheels in the back and hand-clutches. In fact, I met a whole club of three-wheelers and spent a few afternoons touring the countryside as a passenger gaining a completely different aware-

ness of people with disabilities in Vietnam. If I were to live in Vietnam for an extended period of time, perhaps a year or so, I would definitely research this option.

### **Other Venues in Biên Hoà**

To my delight, the newly constructed community square includes a grand library that is fully wheelchair accessible. The library personnel are also very friendly, and the receptionist has a physical disability herself. Again, I was treated with great admiration as a person with a disability carrying out research in Vietnam.

Shops and services, like the post office, vary regarding accessibility. Many small shops are completely open and level to the street so I could just walk or wheel right into the shop. Others may have a few steps, while others are completely closed with large staircases. I believe this is common anywhere one would travel. From my experience, whenever I truly needed assistance, it would eventually be available.

### **Research Assistants**

It is possible to hire local people to assist with various aspects of research. I did not have a regular assistant, but instead employed a family member when needed. However, I was advised to hire assistants at \$10.00 US for a full day's work. This is a considerable salary compared to the usual wages of laborers in Vietnam.

### **Ho Chí Minh City Research Contact**

IEBR, my collaborating institution, is located in Hà Nội, but my work is in the south. For a southern Vietnam research contact, I was introduced to the Institute of Tropical Biology (ITB), also a division of the National Center for Natural Science and Technology. ITB is the location of the National Herbarium (NH), an important place to deposit a set of my plant specimens from the markets. I was given an official letter of introduction from the director of

IEBR to deliver to the keeper of the herbarium. Letters of introduction are extremely important in Vietnam. They are highly regarded and you risk not being seen if you arrive unannounced without one.

The herbarium is not wheelchair accessible. There are two steps to enter the building. The herbarium is on the second floor, the office area and library is on the third floor and the bathrooms are on the first and third floors. There is no elevator. However, the herbarium and library are rich with plant specimens and publications left by the French and other foreign scientists. The keeper of the herbarium, Ms. Trinh Th Lâm, and her assistant are very kind, and I believe if I was not able to access the collections that they would have assisted me by bringing them down to the ground floor.

### **Housing**

Housing is the biggest difficulty for a foreigner with a physical disability who plans to remain for an extended time in Vietnam. I am very fortunate to have family, friends, and the ability to walk. That enables me to have greater choices in my housing. Hotels are usually not wheelchair accessible, except for those that are newer and more expensive. I found information on hotels through an Internet search for "Vietnam hotels wheelchair accessible" and similar searches (Appendix 1). As I stated above, wheelchair accessible hotels are usually the new, expensive ones, especially in Hà Nội (4 or 5 star hotels starting around \$60 US), with slightly more options in HCMC (2 star starting at \$42 US up to 5 star for over \$100 US). Obviously, at these prices, hotel stay is not an option for long research periods.

I am unable to comment about rental housing. I do know that almost anything can be worked out if one truly tries. I recommend highlighting this difficulty and requesting additional funds to pay for accessible housing when applying for grants to do field work in Vietnam

or other international locations (See Appendix 2 for funding sources).

## Conclusion

The experience I have described of conducting research in Vietnam as a person with a physical disability is unique to my abilities, familial and professional contacts. I have made recommendations that I believe would assist those interested in traveling to and in, conducting research in, or living in Vietnam, especially for people with disabilities. I feel that I have been extremely fortunate with my experiences traveling as a person that uses a wheelchair or canes in Vietnam and elsewhere in the world. This is due in part to accepting and accommodating to different situations, but I believe it is largely attributed to the kindness that people have shared. As an ethnobotanist, one of the first teachings is respect and sincerity for all people and cultures. I strive to follow that teaching and believe I have been treated the same.

Everyone has different abilities and experiences at home and abroad. We cannot know exactly what will occur in either place. Thus, with regard to conducting research in Vietnam as a person with a physical disability, I reiterate the earlier cliché, “Where there is a will, there is a way.”

And, again, I pass on John Hockenberry’s statement to me, “There’s no reason to stay home.”

Acknowledgments: I acknowledge and respectfully thank Dr. Nguyễn Tiến Hiệp, of the Department of Botany, Institute of Ecology and Biological Resources (IEBR, Viện Sinh Thái và Tài Nguyên Sinh Vật), of the Vietnam National Center for Natural Science and Technology (Trung Tâm Khoa Học Tự Nhiên và Công Nghệ Quốc Gia) in Hà Nội, Vietnam, and Dr. Jack (Jacinto) Regalado (formerly with IEBR and Missouri Botanical Garden’s Vietnam Botanical Conservation Program), Ms. Trinh Thị

Lâm, curator of the Herbarium at the Institute of Tropical Biology (Viện Sinh học Nhiệt đới) in Hồ Chí Minh City, Mrs. Nguyễn Thỏ Gai and Mr. Nguyễn Đốc Minh, my key informants and mother’s eldest sister and brother, respectively, other family members and vendors of the markets of Biên Hoà city for facilitating my learning and dissertation research in Vietnam.

**My Lien T. Nguyen**, Ph.D. was born in Vietnam of Vietnamese and American parents. In 1975, she immigrated to the United States with her mother, uncle and younger brother. As an ethnobotanist that specializes in the interactions between food customs, plants and the (re)construction of cultural foodways by immigrants, she has explored the markets and foods of Asia, Europe, North Africa, South Pacific island nations, and the United States. Nguyen firmly believes in a “Strong Body – Strong Mind” ethic and has been involved in many programs supporting athletics for people with disabilities, particularly skiing and horseback riding. Contact: mylien@hawaii.edu or mylien\_n@yahoo.com, www.mylientnguyen.info.

## Notes

1. Prices quoted in this report are from the period of November 2003 to March 2004.
2. Ethnobiology Working Group. 2003. Intellectual Imperatives in Ethnobiology: NSF Biocomplexity Workshop Report. Missouri Botanical Garden: St. Louis, Missouri.
3. CITES, The Convention on International Trade in Endangered Species of Wild Fauna and Flora) is an international agreement between Governments. Its aim is to ensure that international trade in specimens of wild animals and plants does not threaten their survival.

## Resources for Travel

- 1) World Hotel Guides  
<http://www.vietnam-hotelguide.com/>  
Advanced Search allows for “Rooms for Disabled” and for Hà Nội returns:  
Horison Hà Nội Hotel  
40 Cat Linh Street  
Tel: 84-4-7330808  
Hà Nội
- 2) BootsNAll  
[www.bootsnall.com/hostels/asia/viet/han/sunway.shtml](http://www.bootsnall.com/hostels/asia/viet/han/sunway.shtml) Lodging listed as “Wheelchair Friendly”  
Sunway Hotel  
19 Pham Dinh Ho  
Hai Bà Trưng Dist  
Hà Nội  
\$42 US  
Manh Dung Guest house  
No. 2 - Tam Thuong  
Hà Nội  
\$10 US  
Legend  
2(A) - 4(A) Ton Duc Thang St. Dist. 1  
Hô Chí Minh City  
84-8-8233333
- 3) Internet resources for accessible travel  
[www.disabilitytravel.com](http://www.disabilitytravel.com)  
[emerginghorizons.com](http://emerginghorizons.com)  
[www.newmobility.com/links\\_view.cfm?link\\_type=community&link\\_category=Travel](http://www.newmobility.com/links_view.cfm?link_type=community&link_category=Travel)

### Appendix 2: Granting Sources and Information

The following are a few organizations that give grants or provide information especially for people with disabilities for education. An Internet search is also helpful.

- 1) Foundation for Science and Disability.  
This is a group of scientists, with and without disabilities that give \$1000.00 grants to graduate students with disabilities in the sciences.

Chair of the Science Student Grant

Committee:

Dr. Richard Mankin,  
503 NW 89 ST

Gainesville, FL 32607-1400

[www.as.wvu.edu/~scidis/organization/FSD\\_brochure.html](http://www.as.wvu.edu/~scidis/organization/FSD_brochure.html)

- 2) Venture Clubs of America: Student Aid Award  
Contact local Venture Club chapter or Venture Clubs of America

ATTN: Venture Coordinator  
Two Penn Center Plaza, Suite 1000  
Philadelphia, PA 19102-1883  
(215) 557-9300

Venture Club of Honolulu

P.O. Box 235137

Honolulu, HI 96823

- 3) Mobility International USA  
[www.miusa.org](http://www.miusa.org)  
MIUSA works in four main areas to provide programs and services including:
  - National Clearinghouse on Disability & Exchange (NCDE)
  - International Development & Disability
  - International Exchange and Leadership Development
  - International Women with Disabilities Leadership and Networking Projects

- 4) The National Clearinghouse on Disability and Exchange (NCDE). The goal of NCDE is to increase the number of people with disabilities in international exchange programs and to assist people with disabilities to have successful international experiences.

NCDE link is available through MIUSA website.

- 5) Michigan State University Libraries database: [www.lib.msu.edu/harris23/grants/3disable.htm](http://www.lib.msu.edu/harris23/grants/3disable.htm)

## No. 1 Piano Paralympic in Japan

Lee-chin Heng  
Malaysia

**Abstract:** The author describes her participation in the first International Piano Festival for the Disabled in Japan in January 2005.

**Key Words:** piano, disability, triumph

One fine day in June, my handphone rang. A Japanese-sounding lady introduced herself as Ms. Akiko. I was working as a piano accompanist in a ballet school then, and she was working in another branch. And through the school, she got my phone numbers. Her university teacher in Japan, Mr. Tokio Sakoda, who is the president of IDP (Institute for Piano Teachers & Disabled in Japan) was planning to host the 1<sup>st</sup> International Piano Festival for Disabled (Piano Paralympic) in Japan at Yokohama on 10–11 of January, 2005, and she was asked for help to look around for participants from Malaysia.

When I received Ms. Akiko's call, it was already very near the deadline for submitting our audition video tape. During Akiko's search for suitable candidates, she got to know Ms. Mei Fong, who is the director of Music Professionals Academy of Performing Arts as well as a music lecturer at University Malaya. Ms. Mei Fong was keen to help out in this event. Together they helped me record the audition tape and send it to Japan just before the closing deadline. Ms. Mei Fong was later invited by the Paralympic Committee to be one of the judges at the Competition.

Around September, I got a call from Ms. Akiko saying I made it to the 1<sup>st</sup> round. This qualified me to perform a variation based on the theme "Sakura Sakura" either arranged by myself or someone else. I needed to prepare and submit the score by November.

I hold a Diploma in Solo Piano and Music Theory, Critique and Literature, but I had never made any arrangement of my own before. So Ms. Mei Fong's friend Ms. Yong Joh Lin helped us improvise as many variations of Sakura as possible. I've always been taught and encouraged to develop my own sense in playing a piece the way I feel it should be played. Through these intuitions and feelings I – together with Ms. Akiko's Midas touch retaining the original Japanese flavor of the theme - was able to edit, transpose, and rearrange the variations.

So finally, on the 7<sup>th</sup> of January, 2005, I departed by myself from Changi Airport, as I live in Johor Bahru, and both Ms. Akiko and Ms. Mei Fong live in Kuala Lumpur. This was the first time I had traveled long distance by myself. The airline which I had chosen to fly by, All Nippon Airlines, was concerned, as from what the ticketing officer in the K.L. branch office told me, they have never before taken a passenger paralyzed from the waist down unescorted. But I am grateful to the officer-in-charge for her very prompt help in contacting both Narita and Changi Airport to ascertain my smooth transition from wheelchair to cabin, and vice-versa, finally resolving the situation with Mr. Tokio Sakoda's assurances that I am fully able to take care of myself. When I checked-in at both Changi and Narita Airport, my seat was already reserved. The seven and a half hour journey on the plane went smoothly. I am grateful to all the staff at All Nippon Airlines for their very kind response and assistance.

At the airport, we were all welcomed and met by our genial host, Mr. Tokio Sakoda, who came personally to the airport to meet as many foreign guests and participants as he could. Mr. Tokio Sakoda did not have more than 1 or 2 hours of sleep, preparing and seeing to all our needs prior to, and during, our stay in Japan for a 67 year-old man-this was really hard on him. During the rest of the day, guests and participants from all over the world, such as Germany, Italy, Poland, Russia, China, Taiwan, U.S.A.,

France, Spain, and Hungary came pouring in. I was the only representative from Malaysia out of ninety-nine participants.

It took about two hours to get from Narita Airport to the National Olympic Memorial Youth Centre in Tokyo, where accommodations were provided by our organizer during our stay in Japan. The Centre is like one big Olympic City serenely enclosed with accommodations, restaurants, arts building, and sports hall amidst the busy and towering skyscrapers outside.

On the 8<sup>th</sup>, we were welcomed to a tea ceremony. It was so important for us foreign participants to have a taste of the traditional Japanese tea and the articulate way it was made and served. Afterward, we were all treated to a performance of a traditional Japanese instrument, the Koto. The lady who played the Koto was so kind as to show me her music score, which is so different from our music notation. The score has been passed down to her from her teacher and their teachers.

At 6 pm, we were given a Welcome Dinner by our host. By then, all foreign and Japanese guests, judges and participants had arrived. We all had such a great time introducing and getting to know each other. After the dinner, the participants were asked to give a short performance and interviews by NHK TV, Japan.

I was told the program was immediately aired on NHK channel the next day, rousing such a great response that people from all over Japan came to Yokohama hoping to see the performances. Unfortunately, all tickets had already been sold.

Early at 8.30 am on the 9<sup>th</sup>, we got on the bus for Yokohama Minat Mirai Hall, one-and-a-half hours away from Tokyo. My performances were divided into two days. On the 9<sup>th</sup>, I performed the “Sakura Sakura” arrangement for the panel of judges to decide whether or not I would make it to the final 18. After my performance, I was able to attend the performances of other

participants at another hall. I saw so many performers with disabilities more severe than mine. They came on stage to perform to let the world know just how much a person with a disability can do even if they needed assistance in holding up their hand to play. I was really touched and my dreams and ambition of becoming a music teacher for the disabled, as well as a music therapist came back to me again. It's hard for disabled persons to find employment in Malaysia, especially in the field of music. Many times I was pushed to the verge of giving up the hope of ever finding a career in music. But whenever I touch the keys of the piano, I am amazed that the music never fails to give me the strength to move on, and the power to hold on to my faith. I am more determined than ever to share this gift God has given me with as many disabled persons as possible.

At last, the announcement for the eighteen finalists came. So many reporters and cameraman from different TV channels were all crowding for a good shot at the name list; my friend Ms. Akiko had to fight her way in to get a good look. And seconds later she was running to me saying my name was on the list! I was touched beyond words. If not for being really late to catch our bus, I think Ms. Akiko and I would have hugged each other and cried.

The next day, I had to catch the first bus at 8.30 am to Yokohama again. I played Haydn's Sonata in E minor, No. 34. Afterwards we went onstage again for a prize ceremony, where every disabled individual was given an award based on their achievement. All the judges awarded me the Technical and Artistic, as well as the High Achievement, Prizes. I got into the next level of competition and performed “Sakura Sakura” again for the final panel judgment. When the result was finally announced, I was so happy that the 1<sup>st</sup> prize went to Sun Yan, who has a visual impairment and is from China. He is amazingly talented. I was fortunate enough to catch one of his performances, and I was truly awed by his talent and the ease of his playing. It was a great



triumph indeed. He is really fortunate to have Mr. Yang Jun for his mentor. Mr. Yang is a well-known music professor in China, with a heart of gold and is a born pianist. Mr. Yang was also invited to Japan as one of the judges.

Second and third place prizes went to representatives from Russia and Poland respectively. Both are amazing pianists in their own respect. The event closed with a farewell dinner celebration, rounding off with the top three prize winners performing their “Sakura Sakura” yet again to our delight. We caught up with last minute photo taking and leaving our contacts with one another. Throughout the two days at Yokohama Minato Mirai Hall, every foreign participant was assigned a volunteer who spoke the participant’s language. That greatly helped us. I was lucky my friend Ms. Akiko is Japanese; she has been such a great friend, assistant, escort and translator throughout my stay in Japan that I did not feel homesick or worried at all during the 5 days I was away from my home and family. Our volunteer Mr. Ishikawa at Yokohama has been wonderfully helpful and kind. He was always running around, making sure of our performance schedule, and checking that our bus did not leave for Tokyo without us. We could not have had a better time than we did throughout the 2 days in Yokohama Minato Mirai. This was the very first Piano Paralympic held, and we all think the organizer did it wonderfully.

We must thank the Japan Foundation and the Piano Paralympic Committee for sponsoring our airfare, food, and lodging expenses. We owe a big thank you to Mr. Sakoda for having put this event together. The event was a dream come true. For the past 10 years, Mr. Sakoda, a former associate professor at Musashino Academia Musicae (Musashino Ongaku Daigaku), a private music college in Tokyo’s Nerima Ward, has worked to show people with disabilities that their condition need not be an obstacle to giving the ivories a good workout. *Otsukaresama deshita, Sakoda-sensei, your dreams have helped us realize our dreams too! Arigatou gozaimashita!*

My friends and I look forward to the 2<sup>nd</sup> Piano Paralympics to be held in Canada in 2009. It is an amazing opportunity for people of different disabilities and countries to be gathered together, sharing the same love of music and mutual regard for each other’s achievements. We hope more countries will come forward with their support and participants and that this event can be brought to all corners of the world. Till we meet again, Sayonara.

**Lee-chin Heng** was born with Osteogenesis Imperfecta (OI), and has used a wheelchair since a bad fall at the age of 7. She and her OI friends have set up a society for people with Osteogenesis Imperfecta in Malaysia. She is a private music tutor and plans to start a music institute one day for persons with disabilities. As music has always been to her what a true friend is like in times of adversity; she hopes to bring this friend to as many disabled persons’ lives as she can and she also hopes people will one day recognize disabled persons for their abilities rather than staring at them wide-eyed. Lee-chin can be contacted at [lc\\_h02@yahoo.com](mailto:lc_h02@yahoo.com) or +6-013-771-2088. She has also set up a website for OI Society [www.oisociety.cjb.net](http://www.oisociety.cjb.net).

## Making an Impact: The Benefits of Studying Abroad

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Project Initiatives Specialist  
National Clearinghouse  
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**Abstract:** Qualitative interviews with ten individuals with disabilities who participated in a study abroad program within the past eight years, compared equally to long-term outcomes cited in studies with the general study abroad alumni population. Students reported increased self-confidence, independence and career or educational gains related to their study abroad experiences.

**Key Words:** international study, career, disability

When a University of Washington student who uses a wheelchair decided to study abroad in Spain, it transformed her outlook on life, her relationship with her family, her college major and her career choices. This is an example of what five months on an international exchange can do.

The term international exchange includes cultural and educational programs that focus on work, study, internship, volunteer, research and teaching experiences overseas. High school students to academicians to professionals to retired community members can participate in these programs, or arrange an exchange experience independently. International exchange programs allow entry into host cultures in ways that are broader and deeper than for general tourists. Students study alongside people from the host country or live with local families. Interns, teachers or volunteers achieve access to the country's employment, educational and social service sectors. Some international exchanges allow a longer stay than permitted under a typical travel visa, making more time available for cultural adjustment and to develop insight

into cultural and language differences. However, exchanges can also be as short as 2-4 weeks, and focused on a specific topic, for example architecture or archeology.

This article focuses on students with disabilities that choose to study abroad while in college. For most students, the study abroad experience will be their first international opportunity. Most will find themselves to be the only, and often the first, student with a disability on the group program or hosted by the counterpart higher education institution.

Is the exchange experience worth it for students with disabilities, given the challenges that may arise in an unfamiliar environment? After students return from study abroad, how are their lives affected, both in the short-term and long-term? How are alumni's perceptions and lives changed as a result of an overseas experience? What are the benefits of international exchange for a student with a disability?

The National Clearinghouse on Disability and Exchange (NCDE), managed by Mobility International USA and funded by the U.S. Department of State, conducted qualitative research that looked at the experiences of ten study abroad alumni with disabilities. All ten alumni had studied during a summer, semester or academic year abroad, sometime over the past eight years, with Council on International Educational Exchange (CIEE) study abroad programs. The students had physical, vision, hearing or health-related disabilities and had studied in Australia, Brazil, Spain and Thailand. Four were young men, and four of the six women were from ethnic minority backgrounds. Unstructured individual or group interviews were recorded by telephone, transcribed and analyzed in the summer of 2004.

### Career and Educational Impact

The alumni provided insights on how they felt their international exchange experience had impacted, or were integrated into, their lives

today. All participants focused the majority of their comments on the effect of their overseas coursework and experiences on their educational and career goals. Study abroad experiences were specifically viewed by some alumni as being well-integrated into their academic preparation toward employment objectives. Some participants also reported personal changes, some of which also impacted career goals. Some comments included:

“Even though my primary reason to go abroad was to perfect my Spanish, then to learn and perfect Portuguese, [the result] was so much more than that. It was also being independent, and getting to know the healthcare systems of those countries. Being in public health now, I speak three languages, I’ve been certified as a medical interpreter and that helps with the job I have now. And the study abroad experience helped me to develop the interest in public health. Not just abroad but here, with all the immigrants that we have in Los Angeles.”

“I think it’s because I went to Spain that I decided to go to law school. [My study abroad experience] is also the reason why I decided to major in Spanish, so it set the path for what I wanted to do for the rest of my life. It’s not exactly about Spain in particular, but when I was over there, there were so many obstacles and it was very difficult. I remember talking to my roommate over there, complaining about this and that and she said, ‘Why don’t you just do something about it?’ so that’s when I started thinking about going to law school and that’s how I went down that path.”

“I’m working at the [center for blind people] as a rehabilitation teacher. I work with seniors mainly. I encourage people to travel with a support group there. I encourage them that no matter what life

brings you, you can overcome it. If you want to travel, if you want to venture out, not to be afraid, but to go for it. I tell them that life is so short, they should enjoy it.”

“There’s a very strong relationship [between my study abroad experience and my career goal] because, for example, at the bank where I interviewed this morning, I was talking to them about international banking...I feel it’s an area of business that I can pursue in the future. I did know a little bit of Spanish, so we discussed international banking.”

“The semester program to Thailand wasn’t what I was doing or studying [international business]. [My later studies at Khon Kaen University in Thailand for eight months] would be more related...it was most useful because it gave me a better view of what Thai business is really like. It was all business courses, and I was the only white guy there, and it was kind of fun.”

“I’m working for a very large import/export firm. I’m working on coordinating international shipments. I was hoping to get into something more related to Brazil, but here in Los Angeles we deal with a lot of Asian shipping. To a certain extent, it does help me appreciate other cultures and dealing with other people overseas.”

Interestingly, respondents that stated the study abroad experience had less significant impact on career goals, were all working in international careers or majoring in an internationally-related course of study—finance, banking, and business. Their responses addressed more directly the question of whether their current international position involved the specific country in which they had studied, or whether the courses they had taken overseas were directly related to their current field. Quantitative interviews with 100 human resources professionals

and CEOs conducted by the Institute of International Education along with three European partners (2003) showed similarities to many employers. The employers recognized the positive qualities that people acquire from an international experience – flexibility, maturity, independence, cross cultural communication skills, ambition – and these same interpersonal skills were desirable qualities in employees. However, they tended not to explicitly link these together to give weight to an overseas experience unless the job specifically involved a cross-cultural, language or international component. This is likely to change, however, as those in the international education field take on greater awareness campaigns of these benefits, and “globalization” and “emotional intelligence” become stronger trends in the employment field.

Research in the international education field has documented these outcomes for study abroad alumni in general. Carlson, Burn, Useem and Yachimowicz (1990) published one of the first significant studies, which included a sample of 150 students from several universities who had recently completed a study abroad program and a long-term follow-up of 76 alumni of study abroad programs from the preceding 20 years. The long-term follow-up revealed, “The educational attainments of the study abroad alumni far exceeded the norms ...on aspiration for and attainment of educational experiences and degrees” (p. 92). Approximately 60% of the alumni reported they had incorporated their international experience into their career choices and employment practices.

Similarly, a decade later the Institute for the International Education of Students (IES) (2000), in a report based on a survey of 3,000 respondents who participated in IES programs from 1950 to 1999, found that 69% felt their international experience had influenced their career choices and 96% “experienced increases in self confidence after studying abroad.” When asked about the highest level of education achieved, 59% of the respondents reported earn-

ing a bachelor’s degree, while 41% had earned a master’s degree or higher.

These studies, while not specific to disability, include what can be seen with study abroad alumni who have disabilities. Related to this focus on employment and graduate school achievement, eight alumni with disabilities interviewed mentioned the overseas experience as helpful on their resumes, in job interviews or on graduate school admissions applications:

“When I was in Illinois and I was calling around because I knew I wanted to do my internship elsewhere, I called California. I called the Center for the Blind and said that ‘I would like to do my internship there.’ The director said, ‘Oh, I don’t know...you are going to move out here?’ And I said, ‘Yes, I’m willing to do it. I’ve been to Australia for nine months with just my guide dog.’ The director said, ‘If you did that then you can come to California!’”

“I had told [my internship supervisors at the World Affairs Center] that I was going to Spain to fulfill my curriculum requirement and that when I returned, I would need to do an internship. I think it did somewhat have an impact on their decision to hire me for the semester.”

“I would think [my international experience helped]. If nothing else, just for the resume value, because it looks good on paper and it is such a good conversation topic.”

“I definitely think it did impact getting my first job. The fact that I had been over to Europe really did help me get an international accounting position, working with an international firm. Just from what they said, I think it gave me an edge over people who perhaps did not have this experience. It also helped too because my boss was from England, and I spent a lot

of time in England. So, I got along with him pretty well and I really understood where he was coming from...They felt more comfortable that I had traveled, but it wasn't necessarily a deciding factor."

"I believe [my international experience helped]. When we went over my resume, we went over my educational history. I'm pretty sure it made a difference when they offered me the position."

"I actually wrote my admissions letter [to Yale University law school] about being in Spain, so I would say [my exchange experience impacted me getting accepted]."

"I go to UCLA. I'm at the school of public health and I really feel one of things that helped me to get in and get a full scholarship was just the broad base that I have...All the times I went abroad, in Mexico, Brazil and Venezuela, the times I volunteered at hospitals and it helped me to write about that."

"I think it definitely helped me get into graduate school because I think that to study abroad, it says something about you. You have certain types of characteristics, that you can adjust to different types of environments, you're a people person."

### **Personal Outcomes: Increased Confidence, Independence**

Other research findings of the general study abroad population also indicate study abroad not only impacts careers, but personal outcomes. Respondents to a survey by the British Columbia Centre for International Education (2001) described their international exchange experience as having had positive or very positive impact on their employment (51%), career choice (77%), acquisition or fluency in additional languages (77%), self-confidence (92%) and independence and autonomy (93%). Similarly, seven alumni with disabilities interviewed reported that by having been abroad, they had

developed confidence and a "can do" approach to other aspects of their lives (educational, social, professional). While some may have had this aspect to their personality prior to studying abroad, they noted a positive increase upon return:

"In my graduate studies, I was taking some classes and people asked, 'How can you take that class? It's really hard. You have to have sight in order to take it.' I said, 'Look, if I'm able to go to Australia and deal with things there, then I can accomplish this. I can do it.' And so they were really amazed. In the end, I still maintained my 4.0."

"Going to Brazil the first time helped me develop better self-esteem and become even more independent. In Los Angeles I live alone, I have my own apartment. I think living abroad, helped a lot with that. And being more comfortable in my [wheel]chair."

"My reality was challenged, and I'm definitely a better person, more independent, more confident. I've matured a lot more. I achieved a lot more confidence about graduate school."

"[I knew] I could do anything if I put my mind into it [after the challenges in Thailand]. Subsequently, I signed up for five courses [upon returning home], which was rather insane. I managed to get a fairly respectful GPA."

"If I get this job coming up, it will be a completely different environment. I've been there, done that, in a way."

"To go abroad, be away for so long without having my back-up system with me, it allowed me to realize that I can certainly do more things than I had thought...For career purposes, it gave me a tremendous boost. If I'm more confident to employ-

ers or whatever endeavor I may be doing, then it's always a plus."

"A lot of times I wouldn't take a class at my school because it was in a building that was inaccessible. I just wouldn't take it. I'd say, I can't take that class, it's fine, I'll take another one. But I think that after being in Spain and seeing that I could accomplish things, when I came home, if I really wanted to take that class, I was going to do anything I could to be able to do that."

This confidence also translated into interactions with family and friends. Five alumni reported family member and friends viewed them as more independent upon return. Others reported no change in relationships with their families, saying they had always encouraged independence, or their families were not involved in their lives:

"I surprised everyone, and it kind of gave me my independence back...For my family, they actually gained confidence back in me – that I can be self-sufficient. I think it made a reality of the future possible in my perspective and also their perspective for me. They became less pessimistic."

"I had a hard time re-assimilating with the people who were used to helping me, my friends and family. I came back and I was very cold to them, I was so used to doing it myself."

"They knew I was scared. They were scared. I had never been away from home that long. I had never been farther north than Tennessee...They were proud of me; they were more confident when it rose in me that I can go out in the real world and survive on my own."

"My friends are really amazed at how much I've wanted to venture out. I don't

want to stay at home anymore. I just want to go out even though I've never been to a certain place. I went half way around the world, now I know I can go anywhere... After I came back, people were more respectful towards me and they didn't try to bring me down. It encouraged me more to reach my goals."

"From the family, none of them speak Spanish. They thought it was a novel experience, but it's totally out of their experience. None of my people attended college, so that's not their world. They all marvel because I have partial vision and I went away. They don't travel in America, let alone abroad."

Four alumni with disabilities also mentioned becoming confident in their ability to travel abroad, and described how their fears were dispelled about participating in an international exchange:

"I was always scared before I had left. Even my study abroad counselor advised me not to do Spain because there are a lot of steps around...Before I had gone, I thought it was so out of reach. When I came back, and I got through it, I was successful and had a good time, it's just a big boost. It makes me think 'I can do this, I can do it again!'"

"For me the most important thing, I was really happy and proud that I managed to do this. I had actually been diagnosed in 1997 before I went over, and I didn't even understand my illness then. Everyone told me that I wouldn't be able to make it, I couldn't survive, I'd get sick. And I did it. And I had a wonderful time doing it, I might add. Just because you're disabled doesn't mean you can't see the world. It may be hard and it may be a little more complicated, depending on your type of disability, but it doesn't mean you have to give up your dream."

“I had never been away from home aside from going to college two hours away...It was hard that first night. I woke up the next morning and said, ‘I’m going to get through this.’ And I absolutely loved it. After the first night, I was fine....I was really scared and concerned about how to maneuver around the airport...But once I got back from this trip and went through the motions a couple of times, I realized that I can do it and there really is nothing to be scared of anymore.”

“I knew it was going to be hard physically, but I was surprised about the emotional challenges of it. It was a total growing process. It was from the initial ‘What am I doing here, this is so hard’ to ‘If I may, I do not want to go home. I love it, this is my home.’...[When I returned home] I worked for a program for people who were going to study abroad. I was an orientation leader and I think that was a nice catharsis for me...that was a good thing for me to reflect on my accomplishments and knowing that I had mastered it.”

### **Changed Perceptions on Advocacy and Identity**

Since many students with disabilities of current college-age attended school in the era of the Americans with Disabilities Act and other disability legislation, they may take access for granted and may not have developed the self-advocacy skills required of the generation previous to them. This often changes when students go abroad. Four alumni with disabilities used the challenges that they encountered in other countries, and in some cases, the better services and access that they found abroad, to recognize their rights as people with disabilities:

“It really changed my attitude. It’s a feeling of pride...I developed certain expectations because I wasn’t going to accept the fact that there was no elevator in this building. That [lack of access] is not OK

anymore. I knew that I deserved [access] and so that’s why I got into law, because I know that there are certain things that I deserve to have and everyone does, and it really took being abroad and seeing the opposite [to realize this].”

“I was angry about [transportation access] when I came home [to Philadelphia]. Because when you’re abroad people say, ‘You’re American, America has everything....’ We’re a powerful country, which we supposedly are, but we’re not using those resources for people with disabilities, because I would like to be able to catch a taxi in my wheelchair. I can’t catch most trains and buses. In Australia, I can use most things like that. Not here.”

“I realized that I may run into some professors [in the U.S.] who will penalize me because I am too sick to go to a class that day, but I will always run into that and I can’t let it bother me. I realize that there is nothing wrong with me asking for help or accommodations, I deserve it. A key difference was that in Spain, the professors trusted you. There was no second-guessing. There was just acceptance. Here, the professors are more concerned about having equality among students, and they see you asking for accommodations as asking for a special favor that they choose to grant...Being in Spain I felt validated.”

“When I was in Australia, I changed in the way that I wouldn’t let people tell me I couldn’t go with them because I had a guide dog...When I was in Australia, I remember I had difficulty with the Disabilities Office there and how they wouldn’t help me and get me a reader. I was very persistent because I was a straight-A student, I didn’t want to fail and I didn’t want to get a B. When I got back [to the United States], the disability office here knew what we needed as people with dis-

abilities, so I have put that devotion and my persistence into other things.”

For some, the change to a different environment abroad highlighted the impact of environmental and cultural conditions on their experience with a disability:

“The taxis were more accessible in Spain. You can literally call them up at your whim and get a taxi with a foldout ramp. It wasn’t mechanical, it’s very simple...It made me feel like any other student. Late night, early in the morning, I could get where I wanted to go.”

“The lifestyle was much more calm, the focus was on enjoying life, it wasn’t on being a workaholic. I have a workaholic tendency, and Spain really slowed down my pace in a really good way. I was much healthier and happier there. I was much less sick, I fit in very well over there...The professors were so accommodating in giving me tests, I really clicked over in Spain. The education itself and studying was harder, but because my accommodations made it easier for me to take tests, it was actually easier.”

“They have pedestrian signals [in Australia] and we don’t have that in Chicago, so that was another thing I had to get used to... The people are much more helpful and very nice, and so I had to get used to the culture in Chicago again, people are not as open and not as helpful.”

Four students also noted the experience created broader worldviews and gave them a different perspective on their identities as Americans. Four others mentioned how it changed their life perspectives, becoming a “defining point” in their lives or confirming their desire to lead lives that incorporated the international realm.

## Increasing Participation

Unfortunately, not enough students with disabilities are taking advantage of these life-changing international opportunities. As study abroad participants in general increase each year and have more than doubled in the last decade (Institute of International Education, 2004), the percentage of students with disabilities (3%), while growing, is still unrepresentative of the percentage of students with disabilities on most campuses (Mobility International USA, Fall 2005). More people in the disability community, who are convinced of the benefits of this type of experience, can help to change the tide by encouraging students with disabilities to seek out these opportunities.

Mobility International USA has promoted international exchange programs since 1981. Co-founder and CEO, Susan Sygall, a wheelchair user who studied for a year in Australia under a Rotary scholarship, decided more people with disabilities should have the opportunity to experience international exchange. Since then, MIUSA has coordinated its own international short-term programs, and in 1995, with funding from the Bureau of Educational and Cultural Affairs of the United States Department of State, established the National Clearinghouse on Disability and Exchange (NCDE). NCDE provides assistance and support to people with disabilities about exchange programs offered by other organizations, such as Rotary International and Council on International Educational Exchange. At the same time, NCDE staff began to educate international exchange organizations and study abroad offices, most of which had little or no experience with people with disabilities, about how to arrange accommodations and services overseas to include individuals with disabilities on their programs. Today, NCDE continues to offer free technical assistance and information and referral services. For insight from other exchange participants with disabilities on a variety of professional, volunteer or study programs, see MIUSA’s *Survival Strategies for Going Abroad: A*



*Guide for People with Disabilities* book, which provides reflections and advice, visit [www.miusa.org/publications](http://www.miusa.org/publications), or contact MIUSA at 541-343-1284 (voice/tty), [clearinghouse@miusa.org](mailto:clearinghouse@miusa.org) to learn more.

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# Optimization of Hotel Reception and Accommodation Service Management for Guests with Disabilities

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**Abstract:** This paper focuses on the requirements expressed by travelers with disabilities in relation to their safety and comfort with reception and accommodation services offered by hospitality organizations, including hotels, motels and guest houses. These findings should open a clearer panorama to hospitality business managers by allowing them to develop better strategies for providing desired levels of friendly assistance and practical facilities. The approach selected is based on statistical methods. The compiled information was obtained via (a) feedback forms given to potential travelers with disabilities, (b) questionnaires given to hospitality business managers, and (c) interviews with hospitality business managers and organizations dealing with people with disabilities in North America, the European Union, Oriental Europe, and countries bordering the Mediterranean Sea. However, the results can be easily adapted to other regions in the world. The conclusions are intended to be useful to people with disabilities and, in addition, to provide valuable information for hospitality business organizations that will allow them to improve their management criteria to retain these important guests while gaining new ones.

**Key Words:** international hospitality, inclusive travel, business management

## Introduction

Travelers with disabilities often have a difficult time finding affordable and accessible lodging. In some countries, such as the United States, there are federal laws that require the trav-

el industry to be more accessible. In other cases, as in most countries of Eastern Europe, there are no visible efforts from either government or the hospitality industry to regulate and provide accessible accommodation. In a global analysis by region or country, there are three main vertexes visible in the interface between hospitality services and travelers with disabilities:

- *The needs of travelers with disabilities.*
- *Governments regulations* related to human rights directed to the hospitality sector.
- *The reaction of hospitality managers* to these needs and regulations in cases where the latter exist.

Each one of the vertexes has a constituency: travelers, government officials and functionaries, and hospitality managers. It is observed that wherever the three constituencies interact closely and evolve together, lodging services more often meet the requirements of travelers with disabilities.

The needs of those travelers are almost the same in every region and country reviewed in this research, but there are remarkable differences in the approach used by governments and hospitality industry managers. According to a United Nations report published in Argentina's *Los Andes Newspaper*, in August 2004, there are approximately 600 million people with some kind of disability (p. 16). In many countries the degree of "inclusion" of that population into society is very limited, if not degrading.

The following data are the results of a survey carried out between May and October 2004. In this study, 133 managers representing 173 hospitality businesses from 21 countries were interviewed. Accommodation pricing ranged between \$30 and \$300 US per person in a double room. It should be kept in mind that the survey and observations reported here are based on opinions expressed by hospitality business

managers and do not necessarily reflect their real behavior.

### **North America: U.S.A. and Canada**

The situation in the United States and Canada for travelers with disabilities can be considered as one of the best in the world. Almost every hotel, motel or other public accommodation priced above \$40 US dollars per person double occupancy, has at least one room for guests with disabilities. The situation in this region tends to be better as a result of the work of a number of well-organized entities such as the Society for Accessible Travel and Hospitality and Open Doors.

A study released by the Open Doors Organization (2002), found that adult travelers with disabilities spent more than 13 billion of US dollars per year on trips. In 2001 the lodging industry took in \$ 4.2 billion, resulting in almost 60,000 jobs created to provide services for people with disabilities. The same study also indicated that this population could double their spending if accommodation improvements were made. This is a considerable slice of the hospitality business “pie” to be ignored by lodging managers.

The above-mentioned Open Doors survey brought to the light what is happening in the disabled travel sector and revealed surprises:

- More than half of adult travelers with disabilities had stayed in hotels, motels or inns in the past two years and 22% were frequent hotel users (3 or more times in the 2 years prior to the study).
- Visitors with disabilities spent an average of nearly \$241 per visit
- Improvements in hospitality services, such as nearby room amenities and more accommodating staff could double their stay.
- Almost 85% of travelers with disabilities

share their travel experiences with others.

### **Survey Characteristics**

- Form of interview: questionnaire feedback and e-mail
- Managers interviewed: 36
- Distribution per country: USA 32, Canada 4
- Number of hospitality businesses analyzed: 51
- Price categories: from \$40 to \$160 US per person double occupancy
- Period of interviews: May – October 2004

### **Results**

Additional factors were discovered in a new survey among hospitality business managers upon which this research is based:

- Almost 94% of those surveyed do not record the visit of travelers with disabilities. The other 6 % survey their reception staff from time to time.
- Ninety-six per cent of those surveyed offer at least one accommodating service, device or element of accessible infrastructure.
- Ninety per cent of managers surveyed are willing to dedicate one staff person to help travelers with visual or hearing disabilities needing assistance, but just 14 % of these businesses take into consideration infrastructure designs or provide appropriate devices to help these travelers.
- One hundred per cent of managers consulted agree that the best services for travelers with mental disabilities are provided when staff personnel are dedicated to meet their needs, but only 80% of managers are able to dedicate staff personnel to assist these travelers.

- Ninety per cent of those surveyed had at least one room or service for people with mobility disabilities; 20% are planning to make improvements in the coming year.
- Despite the fact that 100% of the managers interviewed believe that investments to improve facilities and services for guests with disabilities would be compensated by an increasing demand from these travelers, only 20% are planning improvements for the coming year.
- The main obstacle reported by managers to dedicating personnel or adequately preparing a room for travelers with disabilities is the lack of prior knowledge of the guests needs.

### European Union

The European Union (E.U.) has taken a leading role on human rights issues in the world (Council of the European Union, 2003; European Union, 2004). Its members have been introducing new rules and organizing events like the “2003, European Year of People with Disabilities” as part of their strong human rights defense policies. However, its member states adhere to different administrative perceptions of social policy and thus slow down the process of creating homogeneous rules for all member states. Therefore, no clear and unified requirements for the hospitality industry can be arranged.

On the other hand, the general opinion of hospitality managers is that the European Union must introduce some economic incentives that entice better quality in the services offered to people with disabilities. This lack of coordination between government and hospitality industries appears to be one of the main barriers stopping the development of more accessible and comfortable accommodation for those guests.

### Survey Characteristics

- Form of interview: questionnaire feedback and e-mail
- Managers interviewed: 29
- Distribution per country: Germany 6, France 5, Italy 5, Spain 3, England 3, Portugal 2, Sweden 2, Denmark 1, Holland 1, Czech Republic 1,
- Number of hospitality business analyzed: 43
- Price categories: from \$50 to \$170 US dollars per person double occupancy
- Period of interviews: May – October 2004

### Results

- These venues do not record the visit of travelers with disabilities.
- Sixty-five per cent of those surveyed offer at least one accommodating service, device or infrastructure element.
- Sixty per cent of those surveyed can assign a staff member to help travelers with visual or hearing disabilities and approximately 10% of them are able to provide special devices or accommodation facilities to travelers with visual or hearing disabilities.
- Eighty-five per cent agree that best services for travelers with mental disabilities rely on special attention from the staff and 30% of those surveyed are actually able to exclusively dedicate staff personnel if reservation is made in advance.
- Fifty-five per cent of those surveyed have at least one room or service for people with mobility disabilities and approximately 5% are planning some improvement in the next year.
- Seventy per cent of managers interviewed believe that investments to improve facilities and services for guests

with disabilities would be compensated for by an increasing demand from these travelers but only 6 % are planning improvements for the coming year.

- The main obstacle reported by managers to dedicating personnel or adequately preparing a room for travelers with disabilities is the lack of prior knowledge of the guests needs.
- The introduction of E.U. uniform policies and the lack of economic incentives to accommodate people with disabilities are among the main concerns expressed by hospitality business managers.

### **Eastern Europe**

Eastern Europe has poorly developed the “inclusion” of people with disabilities into society. Therefore, the hospitality industry reflects the situation in the reduced services and facilities offered to those guests. The situation is more a cultural problem of attitude toward people with disabilities than an economic one. For example, many hotels priced at more than \$200 dollars per person per night do not have any service for travelers with disabilities.

Despite regulations provided (Russian Federation Government, 2001), even at constitutional levels, there are no concrete requirements from governments to the hospitality industry to enforce these regulations. Many managers are more concerned with attracting foreign investments than in appealing to travelers with disabilities.

#### **Survey Characteristics**

- Form of interview: personal, questionnaire feedback, phone call and e-mail
- Managers interviewed: 37
- Distribution per country: Russia 17, Ukraine 8, Romania 6 , Bulgaria 6,
- Number of hospitality businesses analyzed: 44

- Price categories: from \$50 to \$300 US dollars per person in a double room.
- Period of interviews: May – October 2004

#### **Results**

- The venues surveyed do not record the visit of travelers with disabilities or make occasional informal surveys of staff on this market segment.
- Twenty per cent of those surveyed offer at least one accommodating service, device or infrastructure element.
- Fifteen per cent of managers surveyed were willing to dedicate one staff member to help travelers with visual or hearing disabilities, but none of their corporate policies or practices take into consideration infrastructure designs or provide for appropriate devices to help those travelers.
- Sixty per cent agree that best services for travelers with mental disabilities rely on special attention from the staff but only 6 % are actually able to exclusively dedicate staff personnel.
- Ten per cent of those surveyed have at least one facility or service for people with mobility disabilities and none are planning some enhancement for the coming year.
- Almost 15% of managers interviewed believe that investments in facilities and services for guests with disabilities would be compensated by a higher demand from these travelers. None of them are planning improvements for the next year.
- The lack of adequate facilities and trained personnel staff, are the major troubles reported by managers in serving travelers with disabilities.
- Governmental subsidies to the hospi-

tality industry (not for people with disabilities) is the most frequent suggestion among managers for effectively improving their services for guests with disabilities.

### **Mediterranean Countries**

(Note: Since Greek tourism is mainly located at the seaside, it is considered here together with countries sharing similar characteristics, despite this country's location in the European Union zone).

Greece is making good progress toward comfortable accommodations for travelers with disabilities, while in Turkey the lack of facilities is, in most of cases, compensated for by the personal attitude of the staff toward travelers with disabilities. Unfortunately the assigned staff is not always sufficiently trained to do that job. In Egypt and Tunisia most of the hospitality businesses offering some accessible accommodation are international brands of 4 and 5 star rating. The overall situation of Cyprus is a combination of Greek and Turkish characteristics.

#### **Survey Characteristics**

- Form of interview: personal, questionnaire feedback and e-mail
- Managers interviewed: 31
- Distribution per country: Greece 9, Turkey 9, Egypt 6, Cyprus 4, Tunisia 3
- Number of hospitality business analyzed: 35
- Price categories: from \$30 to \$170 US dollars per person in double room.
- Period of interviews: May – October 2004

#### **Results**

- Hospitality services neither record the visits of travelers with disabilities nor make occasional surveys among their guests.

- Almost 60% of those surveyed offer at least one accommodating service, device or infrastructure element.
- Sixty per cent of managers surveyed are able to dedicate one staff member to help travelers with visual or hearing disabilities, but none of their businesses take into consideration infrastructure designs or provide appropriate devices to help these travelers.
- Eighty per cent agree that best services for travelers with mental disabilities rely on special attentions from the staff and 50% of them are actually able to exclusively dedicate human resources.
- Twenty per cent of those surveyed have at least one room for people with mobility disabilities and 2 percent are planning some enhancement for the next year.
- Seventy per cent of managers interviewed believe that investments in facilities and services for guests with disabilities would be compensated by an increasing demand from these travelers, but only 2% of them are planning some improvements for the coming year.
- The lack of adequate facilities is the main obstacle to serving travelers with disabilities that was expressed by managers.
- Foreign investments and governmental subsidies to the hospitality industry are the way suggested by managers to effectively improve services for guests with disabilities.

### **Conclusions**

More accessible accommodations are found in the North American region (Figure 1), where almost every reviewed venue offers at least one room or service, including the assignment of personnel staff. However, there is a noticeable

imbalance between managers' desires for improvements and their real financial capabilities, creating an opportunity for the implementation of a credit system. The introduction of a credit or investment system under special regulations and the introduction of strong federal tax reduction policies for travelers with disabilities could allow more where accessible accommodation for travelers exists and provide additional income for the hospitality industry.

It is expected that better conditions in the European Union should be achieved once their state members apply unified policies toward people with disabilities. Eastern Europe appears to be the least receptive, despite higher prices compared with other regions. Mediterranean countries share a common orientation toward personal attention toward their guests, trying to build up a kind of family environment around them. Managers are not only able but willing to help guests with disabilities which at the same time, partially compensates for the lack of facilities.

There are different points of views among managers on the best means to enhance services and facilities. These coincide with social behaviors and approaches to human rights issues in the reviewed regions. Additional differences in strategies toward guests with disabilities were observed. For example, while North American managers are making progress using their own funds, managers in Eastern Europe expect financial support from outside.

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# **Universal Management: A Proposal to Change the Direction of Accessibility Management in the Australian Tourism Industry to Create Benefits for All Australians and Visitors to Australia**

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**Abstract:** In order to realize the full benefits of Universal Design (UD) as a valuable new contributor to the management of access for people with disabilities UD concepts and lessons need to be translated into real decision making and action by boards of directors and managers at all levels of organizations across the world. The development of a concise and clear set of seven principles for UD can be an exciting foundation for management principles applicable to every organization addressing challenges and changes within our communities in the decade to come. Eleven principles of Universal Management are presented for leaders and thinkers in government, judicial, corporate, administrative and organizational spheres of influence. Every manager is invited to rethink the way in which all products and services are designed, delivered and maintained, translating the excellent tenets of UD into new managerial intentions and action.

**Key Words:** management, service, tourism

## **The Opportunity for Change and Improvement**

This paper has been prepared to explore the concept of Universal Management and to encourage the development of a multidisciplinary access project within the Australian Tourism Industry. To date Universal Management has attracted some applause but is understandably slow in achieving its primary goal of developing a new approach to the provision of goods and

services for people with a disability, older members of the community and those whose capacity to travel is temporarily hampered by any one of a range of circumstances.

A range of government and organizational estimates in Australia indicate that at any one time between 20% and 35% of the Australian population requires some additional consideration in the planning and delivery of facilities and services. This may be a conservative number if it includes people identified as having a disability and those for whom disability is not specifically cited but age or other factors impact upon their choices and access to goods or services. For the purposes of this discussion 20% is certainly sufficient to warrant managerial attention, and 35% of any community is sufficient to warrant significant attention to managerial detail (Briton, Deshon et al. 2001, pp. 5-6).

Australian anti-discrimination laws have now been in place for more than a decade. Australia's federal laws including the Disability Discrimination Act 1992, were followed by the introduction of a range of state legislation in the years following 1992 (Australian Human Rights and Equal Opportunity Commission, [http://www.hreoc.gov.au/disability\\_rights/legislation/index.htm](http://www.hreoc.gov.au/disability_rights/legislation/index.htm)). Australia's Tourism Industry now needs to critically assess the gains made, some of which are very impressive, and to address management issues which are seriously impeding further improvement. The benefits this legislation promised have not been fully realized and the reasons for that failure deserve urgent managerial attention.

The development and promotion of Universal Design principles is gradually reshaping the way in which the physical environment will be managed for every member of the community. Universal management is about realizing the full benefits of those opportunities.



## Key Opportunities

- The opportunity exists for considerable improvement in managing disability access issues through the development of guiding principles for Universal Management. This would give managers the practical tools needed to generate significant change and improvement.
- The tourism industry in Australia has the potential to be the pilot sector for a project which would have significant benefits for all Australian businesses, communities and governments.
- The climate exists for a new management model. The world-wide emphasis is shifting to the development of a more inclusive approach by managers while at the same time “delivering the market” to the business community.
- The central concept of Universal Design, “identical whenever possible, equivalent when not,” marks a significant shift in the definition of the Target Market as it is currently understood by the Australian Tourism Industry. A “universal market” is not generally targeted by the tourism sector and the opportunity now exists to reshape some of the foundations of tourism service delivery and marketing.
- Management principles that parallel those of Universal Design would give the Tourism Industry a foundation upon which to develop and adopt an approach based on proactive management rather than anti-discrimination.

As the examples included in this discussion indicate, the Australian Tourism Industry’s marketing flagship, the Australian Tourism Data Warehouse (ATDW), addresses accessibility in a woefully clumsy fashion. It simply highlights the failure of the sector to fully appreciate changes in approach and substance clearly evident in other parts of the world (Tourism Australia,

<http://www.tourism.australia.com/Marketing.asp?sub=0292>).

Tourism industry leaders in other nations are acting in a co-operative and supporting manner through the exchange of information and experience. The national and international work and influence of K eroul in Canada, Mobility International USA (MIUSA) and the European Commission Enterprise Directorate-General are worthy examples for further study. Australia it appears is largely left out of that loop (K eroul, 2003; MIUSA, 2005; The European Commission, 2005). In order to address all of the points listed above, the tourism sector in Australia needs to draw on its capacity to create partnerships. A project of national significance and reach will require a wide range of partners.

It can be argued that there are already too many voices within the Australian tourism industry with forecasting councils, lobby groups, marketing agencies and sectorial representatives from within the industry. Nevertheless, the reach and impact of the industry in terms of employment, property holdings, cooperative business investment and policy development is significant. So much so that a nationally-led project, generously supported with sufficient resources and time, could have a profound impact on the Australian community over the coming decades. The state based structure of the Australian Tourism Industry will present challenges for a national project, but these have been overcome in the past and the benefits would far outweigh the additional effort required to obtain Australia-wide participation.

### At the very least a project should generate:

- A “Universal Management Handbook” for all managers and a set of “Guiding Principles” for Boards and Directors.
- A clearinghouse of information regarding trends and developments in thinking, programs, projects and technologies.

- New guiding principles for service provision in Tourism and Hospitality, a new Universal Service Symbol, Agreed Symbol Sets and Brand Champions. The advent of new methods of establishing and communicating services will need the support of key industry leaders acting as Brand Champions to maintain momentum and build acceptance of the concept.
- A Universal Service National Tourism Advisory Forum. This forum should bring together tourism industry and other leaders to ensure tangible advances are made within the tourism sector and partnerships with all other sectors of Australian life and encouraged to contribute to, learn from and follow the tourism example.
- Training for Assessors, Customers, Employees and the Community.
- Accredited courses for delivery by the Australian colleges of Technical and Further Education (TAFE) network and University MBA programs.
- A register of Best Practice examples, a Supplier Register and an Advisory Service to ensure rapid and comprehensive information for a managerial sector seeking timely information.
- A comprehensive and open review of The Australian Tourism Data Warehouse (ATDW).
- Creative Ideas, Public Awareness, Newsletters and Bulletins and Adapted Principles for other industries.
- Co-operative Projects with international groups and agencies.

### **Australia Ten Years On**

The Commonwealth *Disability Discrimination Act 1992* has been a significant part of the Australian management landscape for over a decade. The act addresses the rights of a subset of

our community and is largely targeted at establishing ground rules and addressing complaints and problems as they arise. Its impacts have, therefore been slight in comparison with other managerial challenges such as the introduction of Goods and Services Tax, labour market reforms and changes to capital gains and company tax rates which reach into the daily decision making processes of every Australian business and household.

This Federal anti-discrimination legislation and its State counterparts have had their greatest impacts in the observance of building codes and standards. There has also been some laudable encouragement of employers to hire greater numbers of people with disabilities. It is best reflected in changes to the wording of job advertisements and the inclusion of ramps and accessible hotel and motel rooms, the provision of accessible toilets and the restructure of car parks to include a number of wider spaces with appropriate signage.

However, in more than ten years there has been no appreciable or demonstrable shift in the basic tenets that apply to managerial thinking within the Australian Tourism Industry. Access for people with a disability remains the province of architects and builders whose primary task is to ensure the minimum standards are met. Adherence to “the standards” is seen as the key to ensuring this subject never arises as a problem for management.

In the Australian tourism sector, few managers, would see the issue as one of importance beyond the need to comply with building codes. This includes owner operators, who traditionally claim a greater emphasis on personalized service. Very few operators would equate anti-discrimination or accessible facilities with a marketing or customer service advantage worth developing. Few would openly accept that an attractive return on investment exists. Few are demonstrating such acceptance through any major focus of managerial time or effort on developing

accessibility beyond the levels stipulated in the building codes.

Accessibility remains largely an issue of exposure to risk and the minimum action needed for compliance and risk minimization. Local Governments are addressing the issue in greater numbers following celebrated court cases concerning difficulties surrounding the redevelopment of a theatre complex in Coffs Harbour. *Cooper v Coffs Harbour City Council* (1988) and the subsequent case *Cooper v Human Rights and Equal Opportunity Commission* (1999) FCA 180 resulted in Councils recognizing the need to be diligent in assessing accessibility aspects of work being done in the city or shire. Other legal actions involving the Redland Shire and Hervey Bay Councils in Queensland further highlight the need to be vigilant in matters concerning standards and approvals. Both councils faced legal action over the standard of buildings and amenities within their local government area ([http://www.hreoc.gov.au/disability\\_rights/decisions/decisions/](http://www.hreoc.gov.au/disability_rights/decisions/decisions/)).

A number of Australian Councils have embarked upon Disability Action Plans and many of these are registered with the Australian Human Rights and Equal Opportunity Commission ([http://www.hreoc.gov.au/disability\\_rights/action\\_plans/Register/register.html#local](http://www.hreoc.gov.au/disability_rights/action_plans/Register/register.html#local)). As yet however, there is little evidence that the business managers and Boards of Directors that control the development of the greater part of Australia's tourism assets view the subject as anything more than a building code compliance issue (Briton, Deshon et al. 2001, pp. 5-6). In 2001 the Maroochy Shire Council adopted the "Maroochy Shire Council Access Policy and Action Plan" which clearly identified the future challenge faced by one of Queensland's leading tourism destinations:

"...The Australian Local Government Association estimates that when these people are included the number of people in the community with disabilities stands

at 35% of the total population. By this reckoning at any one time Maroochy has in the vicinity of 39,000 residents with disability. They all have families, friends and carers.

It makes sense to think of visitors, too, and not just for reasons of fairness or even customer service. It makes good commercial sense in a shire like Maroochy which aspires to be one of Queensland's premier tourist destinations. Maroochy receives 683,000 visitors annually contributing \$260 million to the Shire's economy by spending on average \$98 per person per day yet disproportionately few of these visitors will be people with disability.

Recent research shows that three out of every four people with disability travel less than they'd like to, or don't bother to travel at all, because they can't get to where they'd like to go, can't get out and about if and when they get there, can't find appropriate accommodation, and can't even find out with any reliability what services and facilities are available to meet their needs.

Maroochy is no exception. The market foregone includes not only the 20% - 35% of potential tourists who have a disability, but their families and friends with whom they'd take their holidays. The same research suggests that "Australians with disability already spend \$472 million annually on trips and \$305 million on day excursions, but this would climb to \$5 billion and more if only tourist destinations and holiday accommodation were accessible" (Briton, Deshon et al. 2001, pp. 5-6).

The Maroochy Shire Council Plan recognizes that Local Governments alone cannot address the needs of the entire traveling public. More than a decade after the introduction of anti-discrimination legislation in Australia one leading Council was forced to admit considerable improvements are possible: "if only tourist destinations and holiday accommodation were accessible." The calculations and conclusions reached in the Maroochy document can be

readily applied to all regions in Australia where tourism is identified as an important part of the community's future.

### **Why Universal Management?**

It is intended that the term Universal Management will convey a broad approach to managing spaces and services, as well as all people-related and investment-related decisions. No reference to Universal Management has been found elsewhere and the term has been devised to cover a range of decision making processes and considerations. Universal Management draws together concepts that are gaining acceptance throughout the world and establishes a basis upon which managers within the tourism industry can structure decisions regarding their environment, their approach to service and the foundations upon which they conduct business.

### **Universal Management = Universal Design + Universal Service**

Within this framework, accessibility is a fundamental part of the process – not a legislative or social requirement to be given its own section in the business plan or sub-heading in the design brief. While no single tourism organization is currently addressing all of the issues that relate to people with a disability, there is evidence of a clear directional change occurring in the disability sector's approach to the tourism industry. It is reflected in the energy, time and thought being invested to generate a greater range and number of travel, learning and enjoyment options for people with a disability. This increase in activity on the part of disability service providers represents a real opportunity for the tourism sector to respond and establish the foundation for long term cooperation and expanding returns on investment.

The tourism sector needs to take a positive and optimistic approach to the issue if the benefits are to be realised. To have achieved an on-

going state of Universal Management, the tourism industry will need to be able to show where all elements of its decision-making observe the Universal Design principle, "*Identical wherever possible; equivalent when not.*"

The Advocates Group that compiled the 1997 North Carolina State University *Principles of Universal Design* noted that the principles addressed:

"...Only universally usable design, while the practice of design involves more than consideration for usability. Designers must also incorporate other considerations such as economic, engineering, cultural, gender, and environmental concerns in their design processes."

These Principles establish usable guidelines for designers seeking to better integrate features that meet the needs of as many users as possible (New York Mayor's Office for People With Disabilities, 2002, p. 1). The tourism industry is fundamentally concerned with experiences as well as design but to achieve tangible gains a broad spectrum of research and innovation needs to be addressed to make Universal Management a reality. Managers will need to address factors not previously considered of primary importance when framing service, attraction or accommodation offers.

Much of the tourism planning in Australia remains focused on the economic imperative to achieve the greatest and fastest return on investment (Australian Government Tourism White Paper, 2003). Infrastructure and marketing dollars are invested where they can achieve the greatest impact on attractive target markets and where the business case shows that such investment will "make the difference" for a property, attraction or tour operation.

In adopting a broader view of the expectations of monies spent, the tourism sector will need to recognize that some investments need to target longer term benefits for a wider range

of potential customers. Addressing access needs with a series of property audits and infrastructure upgrades will not generate the levels of return expected of investments in today's market. A holistic and universal approach to access and service is needed to provide ongoing and measurable levels of business growth.

This universal approach will also allow the creation of a broad range of "free" benefits that stem from greater attention to detail on the part of all managers and staff. There is considerable additional goodwill generated through the seamless integration of accessibility with the core elements of any business or service.

### **Universal Design**

In recent years considerable work has been done in America and elsewhere to develop and promote the concept of Universal Design. As an architectural and design industry project, Universal Design addresses seven key principles. Within the Australian Tourism Industry these principles can and should be applied to the design process for all infrastructure planning and design projects, and the development of all new products and pathways.

The definitions listed here are a combination of those provided by the NC State University and those used by the New York Mayor's Office for People with Disabilities (New York Mayor's Office for People With Disabilities, 2002, pp. 19-25). Each of the seven principles can be utilized as the basis for developing a range of management directions and planning activities within the tourism industry. While it will require additional work to extrapolate all the examples mentioned in this report and to create usable management training and planning tools, the seven principles listed are an excellent framework for discussion and further research.

### **Universal Service**

The concepts of Universal Service will be the most difficult aspects of this equation to estab-

lish and maintain. Physical infrastructure can be easily monitored against standards and legislation. Good design is a matter of time and the generation of ideas. The architectural industry is slowly adopting new ideas as they become available, although it is evident that as yet there is insufficient demand on the part of developers and managers to warrant large scale efforts by the architectural community. Universal Service will require an intense collaboration between marketers, managers, product developers and people with a disability.

Almost all customer service information regarding the best forms of interaction with people with disabilities is presented in a non-permanent format. They include information sheets, booklets, and a range of bio-degradable formats that quickly show their age. Similarly, the subject is often approached in a simplistic format that encourages a general reading rather than a serious absorption of fact and an adoption of new approaches.

University subject offerings in Australia indicate the seriousness with which other customer services and consumer behaviours are taken. Customer Behaviour, E-Marketing and a range of Psychology subjects all focus attention on the decision-making processes of the potential consumer. The desires, needs and habits of people with a disability must be afforded the same levels of academic imaging and attention as is spent on other consumer groups and target markets. Customer service information addressing the desires of people with a disability should not be confined to information sheets and booklets punctuated by stylised cartoons and handy hints. Further, it is not sufficient to give a fact-sheet overview of interaction issues and hints and refer managers and staff to a range of disability organisations for further information.

In a major effort to address access in the tourism sector prior to the 2000 Olympics, the Commonwealth Department of Industry Science Tourism, Office of National Tourism

developed and published a kit for tourism operators, *The Tourism Challenge: Access for All* (Office of National Tourism 1997). Within that kit, the section addressing customer service issues provided readers with a range of “do’s and don’ts” and refers readers to no less than *ten* other sources of further information. When considering changes to services and upgrading their staff training, individual tourism operators are unlikely to seek information from a long list of organisations that includes Australian telecommunications company “Telstra” and the “Office of Disability - Commonwealth Department of Health and Family Services.”

Universal Service will require a far greater commitment to the development and promotion of service standards. It will require the collaboration of Government, industry and service provider organisations to establish a “Style Manual” for Australian managers.

Universal Service needs to be a level of achievement rather than a matter of non-discrimination. The tourism industry understands the use of service definitions and other standards relating to its products. Star ratings used to denote quality and the use of such terms as *a la carte* dining and *silver service* to segment experiences have a long history in the industry. While it can be argued that the use of these terms says very little about the personal needs of the customer, the same cannot be said about such terms as *disabled access* or *wheelchair friendly*. Universal Service will address this issue. It is a term that will allow the development of a range of services and service standards for which levels of training and qualification may be developed. It is a term that may be promoted and advertised as a standard that targets all members of the community regardless of age, ability or capacity to pay.

### **The Climate for a New Management Model**

Leading British access consultant Stephen Lloyd, the founder and Head of Diversity Ser-

vices for The Grass Roots Group, highlighted the major hurdle to be overcome in developing a more inclusive approach from managers within the tourism industry. In an interview conducted by the author in London in June 2002, he stressed the need to develop new approaches while at the same time “delivering the market” to the business community, “Everyone talks the business case, but where is the beef? If it doesn’t affect you then the fact remains that business people will continue to see people with disabilities as poor brave souls but assert they have a business to run and a living to earn” (Rice, 2002, p. 27).

The business case and potential size of the market remain important for a strategy to encourage a Universal Management focus in any corporate or business community. The means of delivering a significant and identifiable portion of the market to the businesses concerned will remain a vital element of the strategy. However, in drawing parallels between Universal Design principles and any concerted Universal Management focus, it is important to place the economic and statistical issues second on a list of priorities. The broader principles and tenets need to be established first. These may then be tested against the potential for business success.

In Australia there is a stated expectation by Government and corporate entities to apply a triple bottom line approach to major decisions. Sustainability and success is measured by economic, social and environmental benefits and all decisions need to generate positive outcomes in all three areas. According to The Institute of Chartered Accountants in Australia “triple bottom line” refers to the financial, social and environmental performance of an entity:

“There is a distinct trend towards society demanding more information about the totality of companies’ activities. Whilst company reports have in the past been directed to shareholders and primarily focused on financial information, a wider

group of stakeholders (including employees, local communities, NGOs and other specific-interest groups) are now looking to companies to disclose information about the social and environmental impacts of their activities” (Institute of Chartered Accountants, 2003).

While it is not a general expectation, there is some discussion within museum and gallery networks that the triple bottom line should be expanded to separately address cultural benefits. The Queensland Government’s public art policy “Art Built-in” came into effect on 1 July 1999. Through the Art Built-in Policy, the Government commits 2% of the building project costs towards the integration of art and design by Queensland artists/artworkers (Queensland Government, 2005). Australian business may be forced through political or community expectations to further dilute the economic focus of its decision making with a broader mix of outcome priorities.

The managerial skills required to create a completed “corporate team” already extends to environmental and community relations managers as well as the sales, accounts, human resources and strategic planning executives. As any perceived differences between cultural and social benefits become better defined, the need for a manager of a different ilk may become more pronounced in corporate Australia. The time of the Cultural Manager and the Accessibility Manager may have arrived.

### **A Starting Point**

The architectural and design industry has started the process of addressing universal issues at the earliest stages of:

- teaching and developing the concepts upon which their industry is based, and
- training new practitioners and future leaders.

The industry is harnessing the support of disability service providers, the education sector and major community organizations as partners. There are those within the architectural industry with the foresight and the interest to adopt the new wave of thinking. They will continue to generate a movement within the industry that may eventually overtake all outdated and unenlightened thinking.

The task of the new thinkers will be made significantly easier when the business advantages of their research and design become a sought after commodity. The world’s population is getting older. It is not unreasonable to predict that increasing demand for more accessible product will, over the next decade, highlight the work currently being done in Universal Design and place some new and unique demands on managers and corporate planners.

Managerial support will need to be expressed in mission statements, business objectives and position descriptions. Funding and finance organizations will expect any new approach to be clearly articulated and managers will need to utilize “written expressions of intent” to generate cultural and practical change within the workplace.

### **Developing the Principles**

For Australian communities, agencies and industries to fully accept, support and adopt a changed approach to access, long term goals and shorter term benchmarks will need further development. This may need to be done through industry consultation and the encouragement of academic interest and work.

The Universal Design principles provide an excellent starting point for developing management guidelines. The seven principles do not adequately address such management issues and key decision-making processes as:

- Strategic Planning Decisions.

- Balancing Shareholders and Stakeholder Interests.
- Clarity of Decision Making and Reporting.
- Developing an appropriate Organizational Culture.

The seven principles are addressed below and parallel management principles have been developed for each design focus. The four listed above have been added. For change to be accepted and encouraged, businesses of all sizes will need to generate support in the board room and at operational levels.

In Australia there is a need for a “new start” approach to Universal Management. The structures presented here make no comment on the existing high standards of leadership currently being shown from a range of organizations. Nor do they comment on the considerable gains made in physical infrastructure and workplace reforms etc. Rather, the suggested principles seek to be a starting point for all organizations and individuals to further develop the structures and the networks required to address this issue of access. The best research outcomes and project activities currently available across the world should be combined with the best examples of Australian innovation. A program can then be developed that is attractive to Australian Managers and which can be implemented within the Australian business and service environments.

### **Eleven Principles of Universal Management**

#### **One: Equitable Use**

The design is useful and marketable to people with diverse abilities. The building is usable by anyone. It does not stigmatise or privilege any group of users.

#### *Universal Management Principle 1*

The usability of the building, service or facility will take precedence over all other business planning issues.

- No compromise will be made for economic or other reasons.
- No single group of people will be excluded from the research and testing stages of the project.

Expert advice and creative thinking will be applied prior to commencement of more process-related planning.

#### **Two: Flexibility in Use**

The design accommodates a wide range of individual preferences and abilities.

#### *Universal Management Principle 2*

An active program of testing and improvement will be undertaken involving the widest possible cross section of the community.

- No decisions will be made that will cause any one person or group to be unable to access the facilities or services being offered - rather the planning will be modified to meet all needs.

Where possible the delivery of the product will be constantly “tested to destruction” by a diverse group of employees and potential customers.

#### **Three: Simple and Intuitive Use**

Use of the design is easy to understand, regardless of the user’s experience, knowledge, language skills, or current concentration level.

#### *Universal Management Principle 3*

The service or product will be evaluated regularly and performance measured. Secret shoppers and focus groups will gather ongoing performance data.

- Professional and community groups will be invited to test and comment on all aspects of the business, premises, products and service.



External experts will be invited to examine and comment on plans formulated and the results of implementations programs.

#### **Four: Perceptible Information**

The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's intellectual or sensory abilities.

##### *Universal Management Principle 4*

All internal and external communications will be undertaken in a way that meets the needs of all customers and users.

In the targeting of any niche market or customer group, information will be provided in formats that are accessible to anyone who may be part of that niche.

#### **Five: Tolerance for Error**

The design minimizes hazards and the adverse consequences of accidental or unintended actions.

##### *Universal Management Principle 5*

In all areas of the business, positive provision will be made for a potential user's lack of experience, knowledge, language skills, or concentration level.

Difficulties experienced by any individual customer will be recorded and examined for improvement options.

#### **Six: Low Physical Effort**

The design can be used efficiently and comfortably and with a minimum of fatigue.

##### *Universal Management Principle 6*

Sufficient resources will be made available to ensure availability of appropriate facilities at all times.

All aspects of the facility or service will be tested for ease of use. Staging of all tasks will become an expectation in planning.

#### **Seven: Size and Space for Approach and Use**

Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.

##### *Universal Management Principle 7*

In all decisions regarding resources for staff, customers, visitors or residents, a generous approach to allocations will be expected.

The supply of additional resources ensuring full inclusion of all members of the community will encourage returns well beyond any initial outlay.

#### **Eight: Strategic Planning Decisions**

##### *Universal Management Principle 8*

People with disabilities will be actively engaged in the strategic planning processes of the organisation.

Employees of the organization and members of the community will be invited to participate.

#### **Nine: Balancing Shareholder and Stakeholder Interests**

##### *Universal Management Principle 9*

In all communications with Shareholders and Stakeholders the value of Universal Management will be clearly explained.

The objectives of the program will be placed second only to the fiduciary responsibilities of the Board of Directors in importance and emphasis.

#### **Ten: Clarity of Decision Making and Reporting**

##### *Universal Management Principle 10*

The decisions and actions of the organisation will be clearly outlined in all ongoing communications to employees, customers and shareholders.

This will include:

- Processes to achieve desirable outcomes and address any difficulties encountered and any limitations to the organisation's capacity to reach full implementation of Universal Management principles.

### **Eleven: An Appropriate Organizational Culture**

#### *Universal Management Principle 11*

All aspects of the organization's day to day operations will be utilized to build the highest levels of understanding and appropriate response to the challenge of Universal Design and Universal Service.

### **New Definitions of the Target Market**

For many years, Australia has maintained intense country-specific marketing programs in the United States, Japan, the United Kingdom and Korea among others. Further research may indicate that the demand for international "Accessible Tourism" experiences is resulting in huge amounts of disposable income being spent in destinations other than Australia. If we accept that our Nation's marketing is effective and customer awareness of Australia is increasing, then clearly this group is actively choosing other destinations for reasons that need to be addressed.

The potential for growth through a greater focus on people with a disability is gradually becoming clearer. Research being undertaken throughout the world is starting to give an indication of the numbers of people with a disability intending to travel.

In 2001, K eroul undertook a major survey of Canadian residents with restricted physical abilities and published a summary report entitled, *"A Growth Market: Behaviours of Tourists with Restricted Physical Abilities in Canada."* That report identified that 28% of physically disabled people travel outside Canada. Of those surveyed 15% traveled to the United States and 13% traveled to other international destinations (K eroul, 2001, p. 9).

As yet this research is not of a consistency to compare with other target market data available in Australia on, for example, Scandinavian backpackers, Japanese honeymooners or British family members (Tourism Australia, 2003). Suffice to say the numbers being revealed in research to date run to millions of people with million of dollars of disposable income. The exact scope of the target market needs to be the subject of intensive research which would need to be undertaken in collaboration with overseas tourism partners.

In Australia there is only anecdotal evidence of the extent to which access issues are given any primary consideration in planning and ongoing service development. Managerial effort is largely measured through a stated willingness on the part of all concerned to comply with the current legislation. As in all world tourism markets, the delivery of a satisfactory Australian tourism experience depends heavily upon the consistent supply of high quality products from almost every sector of the business community. Correspondingly, growth in the tourism sector has an almost immediate flow on effect that generates growth in other sectors such as transport, personal services, printing and publishing. The tourism sector traditionally researches and targets market sectors that have the most potential for the greatest return on marketing and infrastructure investment.

As target groups become more minutely defined there is a considerable cross-mixing of target groups and individual travelers fit the format for a number of accepted definitions. The "Empty Nesters" and the "Luxury Group" may have a very high number of members in common. Backpackers, Eco Tourism and Adventure Tourism are all concepts that are marketed with a range of common experiences being offered (Tourism Australia, 2003). Similarly the access and disability markets are not always clearly defined sub-sets of the traveling community and yet the industry continues to define "disability" as a niche market in its own right with little or

no cross over with target markets. In 2003 the Australian Government released a document outlining a medium to long term strategy for tourism.

Some potential niche markets include seniors, defense, culture and the arts, sport, backpacker, health, people with disabilities, caravanning and motor homes, cycling, food and wine and agritourism. This list is not exhaustive (Australian Government Tourism White Paper, p.31). When this *niche market* tag is applied the way is opened for managers to adopt mind-set that would not be applied to other target markets.

The historical or legislated approaches encourage or enforce:

- The adaptation of services and facilities to meet the special needs of people with a disability.
- The outlawing of discrimination against people with a disability and the establishment of tribunals and other authorities to address complaints and transgressions.
- The encouragement of workplaces and other areas of community life to address ways in which people with a disability can be “integrated” into areas of their workplace or operation.
- Carefully worded expectations or requirements that apply only when major refurbishments, changes in purpose or growth thresholds have been reached in business or community establishments.

While there is no doubt that individual managers in Australia’s tourism sector do afford the issue the amount of consideration required under legislation and regulation, the reliance on checklists of building regulations and using an anti-discrimination approach often leads to:

- Consideration of physical and design

aspects of construction being left to architects and draftsmen with an expectation that the design will meet current requirements.

- An expectation that staff will have a broader understanding of anti-discrimination than they might in fact have.
- A belief that generic service standards and operational instructions will meet the needs of all customers and that staff experience will make up for any difficulties that arise with individual customers.
- A belief that all accessibility measures are an imposition on the business.
- A belief that accessible facilities and services are for a minority of customers when the business is attempting to maximize its patronage.
- A belief that any retrospective work on accessible facilities and services will be an expensive imposition on the business with little hope of a positive return on investment.
- A perpetuation of the belief that the business needs to make some concessions for people with disabilities, but it is not part of the core business of the organization and warrants little ongoing time or effort.

Universal Design requires, at a physical level, seamless integration of access into our environment for all members of the community. This concept is new to the architectural and design communities and has the potential to generate considerable discussion and change in managerial and strategic planning spheres in coming years.

The concept of target markets within business or community planning is arguably at odds with the principles of Universal Design. The categorization of people with a disability as a

small niche market opens the way for strategic planners and managers make service and product design decisions that heavily favor one sector of the community over another. This needs to be carefully weighed against a broader commitment to social and business equality. Any shift toward Universal Management would mean that segregating one section of a service or facility to meet the needs of “those people” while the rest use “the normal facilities” must become an outdated form of managerial thinking.

In the future, any attempt to create a definitive category of clients having special needs will be fraught with danger. From a business perspective, the development of a “one size fits all” offer or product will surely be flawed if we take out those who fall into one or more of the special needs categories. It may be expected that when the “normal” population becomes the minority, and that case might well be argued at this time, managers who do not embrace some form of Universal approach to the community at large will see their target markets shrinking. The challenge for managers will be to better tailor their product for a major new sector of the community as well as their existing customer base.

This “new majority” in the community will select products and services using a different set of criteria to those of the past. In the initial stages personal preferences relating to choice of color, peer group pressure, proximity to the beach and a desire to create more leisure time or greater wealth may give way to a significant recognition of being respectful, polite, practical and welcoming.

This does not mean that all facilities will be exactly the same. On the contrary, the broadest range of services delivery and infrastructure related options may be presented within the same space. It does mean, however, that issues of equitable access to all facilities and equal opportunity to enjoy the benefits of the goods, services and attractions offered needs to become a high

priority in any planning and implementation activities. It could reasonably be expected that managers implementing a Universal Management regime within their planning and implementation would initially address the following issues.

The intended business, service or organization should be equitable with respect to:

1. Services being delivered to all potential clients or users.
2. Physical design elements being incorporated into all spaces utilized.
3. Product and service expectations being generated and communicated to visitors, clients and users.
4. Goodwill and community support being encouraged and fostered.
5. Creativity and research being commissioned or undertaken.
6. Education and training being undertaken with employees, clients and users.
7. Observance of regulatory, due diligence and legislative requirements.
8. Allocation of investment funds and operational spending.
9. Generation of a respectful, dignified ethical culture within organizations, industries and communities.

These nine areas of managerial responsibility will have a significant influence on the basic framework from which the Universal Management principles are developed and implemented. The potential exists to re-examine all supply and demand, human resources, and marketing and investment theories with a view to generating a sustainable approach to access. That re-examination will extend well beyond the anti-discrimination and minimum requirement focus evident in so many businesses around the world today.

At the moment, much of the responsibility for delivering respect, politeness, practicality and warm welcomes is left to the front line troops within our business community. Staff members at front counters, telephone operators and delivery personnel are the bearers of much of the goodwill in a business. This may not be enough. Product designers and market researchers may, in coming decades, struggle with the concept that many of their products are being left on the shelf due to the lack of a holistic approach to the community's needs.

This potential shrinkage in future markets for some businesses may be evident no matter how well defined the target market is or how much of that market the business is targeting. A change in social expectations and community norms will generate a negative impact upon a business as surely as any ill-targeted marketing plan.

To achieve the changed approach required under Universal Management, all facilities and services must be developed with a real commitment to ensuring they are accessible to all people. It is not a program of addressing individual problems that already exist. Universal Management requires a complete reengineering of the business ethic and methodology. The SWOT analysis framework goes some of the way toward achieving this with an assertion that managers should ensure their enhanced facilities are utilized to the "benefit of all guests." The process of achieving solutions however, will need to begin well before this point.

### **A Tourism Insight: The ATDW – Australian Tourism Data Warehouse**

While people with a disability remain a remote group of customers, the tourism industry will continue to group this community with other optional market segments. In recent years the Australian Tourism Industry has invested a significant amount of money in the development of the Australian Tourism Data Warehouse (ATDW) (Tourism Australia, 2003). In

itself, the ATDW is an ambitious and laudable project addressing the substantial need to gather and disseminate information directly to all levels of the industry and to potential customers. The ATDW data input screens are complex and have been designed to accept information about the widest range of accommodation, attractions, regions and products.

However, it could be argued that one of the most expensive information tools ever developed for the tourism industry is disappointingly lacking in its capacity to provide information where it is most needed. People with a disability are the group that needs the highest levels of information prior to leaving home and the deficiencies of the ATDW system will soon be judged by the marketplace.

ATDW does provide a clear insight into the difficulty the Australian Tourism Industry has in separating people's needs, responsibilities and expectations. People with a disability as a market segment operators may choose to target or choose to reject. Tourism properties do not tailor their product offerings to attract or repel people with disabilities – or at least they shouldn't. In fact any property that fails to tick the appropriate box should be open to questioning about why they perceive their product is not suitable for all members of the community wishing to visit.

With respect to facilities and infrastructure, a vague two-tiered system with space for notes places the issue of disability in the same category as the BBQ facilities and a bike rack. Yet another area of the ATDW system places the access issue within another well defined area of managerial attention. It is, however, difficult to imagine how an industry which is built upon providing the greatest number of recreational and leisure opportunities for the greatest number of people might place people with a disability, children and pets under a single heading called special needs. Rather than a "special need," it should be a system of services and considerations that

ensures there is no discrimination in the delivery of whatever recreational or leisure experiences are being offered.

### **Tourism as a Catalyst**

Suitable industry and community liaison and promotional structures need to be created to engage the wide range of organisations and individuals required to implement a fundamental change in managerial thinking and planning in Australia. “Whole of Government” and “Whole of Community” approaches are needed if significant expansion in the capacities of Australian management and governance is to be achieved. This expansion will need to embrace the concept of Universal Management as an extension of Universal Design and the creation of Universal Service. The tourism sector in Australia is however, uniquely positioned to achieve such a change in thinking and action.

Unlike many of the other recognised industries that form the bulk of the Australian economy, the tourism industry influences and enhances the interests of all sectors of business, community and the environment. It is a loose-knit coalition of small to medium sized businesses along with a small number of major companies. It generally works within a framework of representative organisations and government departments, which gives it the status of a cohesive industry sector. As such the interests and influence of the tourism industry extend to:

- Legislation
- Federal, State and Local Governments
- Building Management and Infrastructure Development
- Roads, Signage and Transport
- Training and Education
- Environmental Management
- Retail and Services
- Agriculture and Regional Business

Very few other industries draw upon the same range of resources and depend upon the professional service standards of such a diverse segment of the business sector. The Australian Tourism Industry has the capacity to generate a fundamental shift in thinking; however partnerships will need to be developed to achieve this outcome. The relationships tables below indicate the range of synergies that will be needed to fully achieve the gains that are possible within the tourism sector. All groups identified are already engaged in the processes of policy formulation, market forecasting or targeted marketing. The relationships may need to be renegotiated or new social and business contracts established to encompass Universal Management principles.

The tourism industry has generated considerable cooperation and synergy in drawing together varying groups of partners to examine forecasting, employment, sustainability, environment and taxation. As yet this capacity to create partnerships has not been used in any significant way to address the broader issue of access management.

The capacity of the Tourism industry to engage such a cross section of the Australian community and business sector means a comprehensive framework may be used to establish an industry-specific series of consultations and opportunity identification projects.

Universal Management will require balanced input from leaders with expertise in legal, commercial, investment, consultative and human resource fields. The Universal Management framework seeks to ensure managers understand the social, moral and personal backgrounds to service and infrastructure decisions. It will be imperative that each of the major tenets upon which society is based are represented in the formulation and ongoing development of the Universal Management concepts.

Given the range of relationships, responsibilities, interests and investments that impact upon or influence the Australian Tourism In-

dustry, important areas of endeavor can be identified for an immediate start to project development and industry implementation. The industry needs to give detailed consideration to:

- Developing usable managerial training tools.
- Collating the best of the world's collective knowledge and research.
- Monitoring improvement and advertising advantages of an accessible Australian holiday.
- Engaging and empowering people with a disability.
- Creating improvement that will meet the needs of the industry in coming decades.

A nationally-led project engaging all partners and stakeholders in the tourism industry would provide Australia with a major platform for generating improvements, knowledge and attractive returns on investment.

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## **Disability Classics**

### **How Long Must We Wait? Unmet Promises of Disability Law and Policy\***

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#### **Introduction (Beth Omansky, January, 2006)**

In "How Long Must We Wait," Mike Oliver and I chronicle the mistreatment of people with impairments by disabling transportation systems, and how these restricting policies and services limit access to such simple freedoms as getting together with friends and colleagues. Ill-treatment of disabled people occurs so frequently as to become mundane. We learn to expect that each new day might unfold into an exercise in frustration, ignorance, or maltreatment. If we complained every time we experienced such behavior, we would exhaust ourselves. Anyway, would our grievances be heard?

To my surprise, when I related my disappointment over not being able to get together with my British colleagues, my former professor, Karen Rosenblum, asked, "Will you and Mike write this transportation story for the third edition of our book?" (*The meaning of difference: American constructions of race, sex and gender,*



*social class and sexual orientation*. NY: McGraw-Hill, 2003). Evidently, what was a “typical” story of our day had larger import and deeper impact than I could discern from my location as a person accustomed to being disabled by public transit.

Mike’s and my story is not unique by any stretch of the imagination. Despite fifteen years since implementation of the Americans with Disabilities Act of 1990, accessible public transportation remains unreliable, undignified, and sometimes unsafe. Travel expenses are not merely monetary. Often, public transportation costs lost time, stress, physical setbacks and injuries as well as destruction of essential personal property.

One colleague whom I shall call “Dillon” (he chose to remain anonymous because of ongoing settlement negotiations with an American air carrier) experienced mistreatment of both his body and his wheelchair. First, during transfer from his wheelchair into the airline’s chair, one of the employees stopped holding Dillon, causing him to fall toward the floor. He believes that having one person in charge who would coordinate the critical transfer process would help prevent such slipshod practice.

Before leaving his own power wheelchair in the hands of airline employees, Dillon and his partner instructed them several times to take the expensive, custom-made chair by elevator to the airplane cargo hold. Once settled into his airline seat, Dillon and his partner watched in horror as his wheelchair was bounced down the jetway stairs, knocking the battery onto the tarmac.

Upon reaching their destination airport, Dillon was forced to sit in a custom issue airline chair while the airport workers took him to his wheelchair (rather than bringing his wheelchair to him) and tried to fix what they had broken, causing injury to Dillon’s skin. Skin abrasions are a significant concern to wheelchair users since it takes a long time to heal and each new abrasion leaves the skin more vulnerable to future

injury. As the result of the wheelchair damage and subsequent repair time, Dillon was without his wheelchair, “stuck in bed for a month,” disabled by ill-trained airline employees.

With regard to the current state of in-city ground paratransit, the topic of my portion of the following article, I have heard similar stories from both paratransit drivers and passengers in the three cities in which I have lived over the last five years. On-time pickups and drop-offs are thwarted from the start because of poor scheduling and unrealistic routing of ride shares. Passengers routinely find themselves riding in vans for hours on trips that should take no longer than twenty minutes. Dialysis patients are often left waiting at the dialysis clinic for several hours or forgotten altogether, having been inadvertently left off driver manifests. Riders have lost potential jobs because paratransit vans have caused them to arrive at interviews more than half an hour late. Reliable, on-time transportation is imperative for many disabled people attempting to enter or stay in the workforce.

On top of service delivery problems, each paratransit district has its own policies regarding eligibility for service. Some districts determine rider eligibility based not on whether the person is truly eligible under the ADA, but rather on how well or poorly funded each local system is. For example, when I lived in Tucson, Arizona, I was deemed eligible to ride only from 7 a.m.-10 a.m. and 7 p.m.-10 p.m. because their vans were full during mid-day hours. After I appealed this ruling, the Appeals Committee decided I could ride anywhere during the previous hours and also during the rest of the day as long as I scheduled rides farther than two miles in any direction from my home. Evidently, they reasoned I became blind enough for them during specific hours and only outside of an arbitrary perimeter. Conversely, with the exact same level of blindness, I was declared eligible with no time or distance restrictions for paratransit in Washington, D.C. and Portland, Oregon, with no extraneous bureaucratic roadblocks. The

good news is there is such a thing as paratransit, all public transportation is required to accommodate disabled people, and services are slowly improving. In a recent E-mail exchange, Simi Linton wrote that:

“...Significant changes in the availability of accessible public transportation. I travel by air a good deal, particularly in recent years. It is much easier now than it was in the 70’s and 80’s. The subway in New York City is not at all accessible, but as of four years ago, all the busses have lifts (although they are not always in working order), and the drivers are usually efficient and courteous. However, while there is progress, most public transportation systems are inaccessible and unusable by many disabled people. Disability still marks me and others in most places that we live and travel. We should note the changes, but remain vigilant about the discrimination that continues in public transportation and accommodations.”

Transportation-related services for disabled people remind me of the old nursery rhyme about the “girl with the curl in the middle of her forehead: when she was good, she was very, very good, but, when she was bad, she was horrid.” When disability-related accommodations work well, they bring freedom of travel to work, to participate in the consumer economy, to get to and from medical appointments, to go to school, houses of worship, cultural events, and to be with friends and family. The stories Mike Oliver and I tell illustrate what happens when “she was horrid,” when the systems for disability accommodations fail to live up to the promise of full inclusion of people disabled by discriminatory environments and institutional practices.

### **How Long Must We Wait? Unmet Promises of Disability Law and Policy**

#### **All We Really Want to Do**

In the fall of 2000 we were invited to attend a prestigious international conference in Wash-

ington, D.C., to launch the discipline of disability studies onto the academic world. We eagerly accepted the invitation and looked forward to a stimulating few days in interaction with academic colleagues from around the globe. This is a scenario not unknown to many thousands of international academics. However, we would argue, our experiences as disabled academics set us apart from those of our non-disabled colleagues because of the discriminatory treatment we face in doing ordinary things that our non-disabled colleagues take for granted; in this case, using public transportation.

We recognize that using public transportation can be a difficult experience for all concerned, but our experiences as disabled travelers go far beyond what the non-disabled traveler has to endure. When millions of disabled people all over the world still have their basic human rights denied to them, we feel uneasy about highlighting the personal difficulties of a few relatively privileged ones from the minority world. But as academics working in a discipline where personal experience is seen as pivotal to our understanding of the world and the ways it operates, we make no apologies for describing our own discriminatory and degrading treatment though we will try to use these personal experiences as a framework for broader analysis. In so doing, initially Mike will describe his experiences of flying to Washington, D.C., for the conference and then Beth will discuss her attempts to use the local transportation system to socialize with academic colleagues. We will then end by considering some of the general issues raised.

#### **Leaving On a Jet Plane [Mike]**

When I received an invitation to attend the conference in Washington, D.C., I was unsure whether or not to accept because it would mean that I would have to fly from Britain to the United States and I have had many unpleasant travel experiences in the past. I have been ignored, abused, patronized, dropped on the floor and often handled worse than the dead meat that is served to the passengers on the flight, all because

I use an electric wheelchair and require manual assistance. It seems incredible that when we have the technology to send people into space we still find it difficult to enable disabled people to get on and off airplanes with their dignity and self-respect still intact. However I decided that the promise of the conference plus the opportunity to socialize with other academics with interests similar to mine was too good to miss.

The first hassle, I knew from experience, would be in trying to find an airline that would permit me to prebook seats that would give me enough legroom to enable me to sit comfortably and safely. "It's not allowed," "IATA regulations don't permit it," "It's up to the Captain," "We don't know how the plane will be loaded," "You're not allowed to block exits," "We don't know what plane we will be using" are all excuses I have been given in the past. After several angry phone calls and an exchange of letters, I am eventually allowed to book seats which will give me the legroom I require and I know that the first battle is over.

When I check in at Heathrow, London--one of the world's busiest airports, the staff insist that I transfer out of my electric wheelchair and into one of their manual ones. I explain that that will mean me sitting in an uncomfortable chair for at least three hours as well as restricting my personal mobility. The equivalent for a non-disabled traveler would be the enforced wearing of someone else's shoes whilst being denied access to refreshments, duty-free shopping and so on. My request that I be allowed to remain in my own wheelchair until I board the plane is turned down on health and safety grounds. I am told that the ground crew will not lift my wheelchair down the stairs from the gate to the tarmac for stowing in the hold.

Reluctantly I agree to get out of my chair and, after a few minutes wait, two men turn up with a manual wheelchair and proceed to lift me bodily into it, in full view of those queuing for the flight as well as anyone else who wants

to watch. This was managed competently but I feel that it is hardly appropriate treatment for anyone to endure. The two men then try to dismantle my electric wheelchair and disconnect the batteries. I explain that the chair does not dismantle and the batteries are dry cell and do not need to be disconnected. They tell me that they must disconnect the batteries and I insist that it is unnecessary.

At this point my wife, Joy, who is traveling with me as my personal assistant, intervenes and calls the supervisor. After a heated argument and several phone calls, it is agreed that dry cell batteries do not need to be disconnected and the men and my wheelchair disappear into the bowels of the airport. As I watch it go, there is no guarantee that they, or the ground crew who will lift it into the hold, will not disconnect the batteries or indeed, remove them altogether. The experience of a friend of mine briefly comes to mind. She flew from Heathrow only to notice that her chair was still on the ground as the plane took off: Not only had they refused to load it but they had also neglected to tell her.

Some two hours later I am taken to the gate for boarding. I am told that I will be loaded before the rest of the passengers which would at least preserve my privacy, if not my dignity. Unfortunately however, the two men designated to carry me on to the plane are late and only arrive as other passengers are being boarded. This means a further delay until I am to the door of the aircraft. On reaching this point, a small lifting chair is produced and I am transferred from the airport wheelchair onto it. It is wholly unsuitable because it has no arms and does not take into account the fact that I have no balance. Eventually I am strapped to it and carried onto the aircraft which is now full.

I am carried past row after row of passengers until I reach my seat. I am then lifted bodily into the aircraft seat but there are a number of problems with this. The space is very confined and does not give the lifters much room and the

arms of the aircraft seat are not detachable. As a consequence of this I am virtually dragged over the arm. What physical damage this is causing I don't know as I have no sensation in that part of my body but the dragging does pull my trousers down and exposes large amounts of naked flesh to the rest of the passengers. Eventually I am placed in the seat and my wife helps me to rearrange my clothing. I now settle down for the nine-hour flight but realize that I must moderate my food and liquid intake for it is impossible for me to get to the toilet on the aircraft.

We arrive in the Washington, D. C., airport and a row then breaks out between airport staff and cabin crew as to whose responsibility it is to get me off the aircraft. This causes delays and clearly angers a tired cabin crew who want, quite rightly, to get off the aircraft themselves and end their shift. The situation is eventually resolved when a member of the cabin crew and the flight engineer agree to lift me off the aircraft. This they do, but they are not trained so to do and once again I am dragged across the seats and my clothing again comes adrift.

In the terminal, I am informed that I must now transfer into one of the airport wheelchairs before proceeding to the collection point for our suitcases and my wheelchair. There are two problems with this: their wheelchair does not have detachable arms and there is no one to lift me. Another row breaks out and eventually two airport staff volunteer to lift me into the airport's chair. Again this is managed with great difficulty and some danger to all of us as they are willing but untrained.

Eventually I am reunited with my own chair and I begin to relax. I decide to complain formally and demand to see someone in charge. A supervisor appears and informs me that getting on and off the aircraft is my responsibility and that I should have been lifted off by my wife and two colleagues who are traveling with us; one [colleague] is himself disabled and the other has a history of chronic back problems. At this

point I leave as I desperately need a drink and to get to the hotel to survey any damage that may have been inflicted. Once I am in bed I find that I have severe lacerations and bruising to my buttocks. It takes me several hours before I am able to stop shaking. Still I am here and I look forward to the next four days though in the back of my mind I know I have to go through it all again in order to get home.

### **Everything is Broken [Beth]**

Knowing that my British colleagues have a predilection for American blues music, I make reservations at a supper club where we will meet. I first met Mike and his colleague, Len briefly at a conference in Chicago earlier in the year, and I found much in common with them. I am excited at the prospect of spending Sunday evening socializing and exchanging ideas with internationally renowned scholars on the first night of their visit to Washington, D.C.

Mike calls my home at about three o'clock on the Sunday afternoon of their arrival to say they are finally settled in at the hotel. He sounds perturbed, apparently due to mistreatment by airport employees, but still wishes to get together. We decide to meet at seven o'clock that evening. Mike will contact the D.C. taxicab company to arrange for a wheelchair-accessible van.

About half an hour later, Mike calls back with our first piece of bad news: there is no wheelchair-accessible taxicab service to travel from one location to another within the District of Columbia. While you can go from D. C. into the Virginia or Maryland suburbs and back into D.C., the taxi service will not take you between locations within the District. I am astonished and baffled by the logic of this policy. I wonder if this is just a means to charge more by forcing disabled people to take lengthy detours into the suburbs and back again, or to discourage them from riding taxis altogether. We forego any plan to find another music club that is both wheelchair and distance accessible, and choose instead

to find a restaurant near the hotel where Mike, Joy, and Len are staying.

I plan to take the nine-mile ride from my home into the District via MetroAccess, the D.C. metropolitan area's paratransit system for disabled people. The Americans With Disabilities Act of 1990 (ADA) is a civil rights law designed to prohibit discrimination and to ensure equal access to transportation, employment, public accommodations, public services, and telecommunications. The law mandates paratransit service, usually comprised of a fleet of wheelchair-accessible vans and perhaps some cars. The Washington Metropolitan Area Transit Authority (WMATA) sponsors MetroAccess paratransit service, but subcontracts the work out to local governments and other local fixed-route transit systems, including privately owned for-profit companies in the metropolitan area.

Being considered disabled under the ADA is not enough to be considered eligible for paratransit ridership; disabled people must go through a certification process. Applicants must complete a lengthy, two-part form, Part A to be filled out by the applicant, Part B to be completed by a physician. Eligibility is based on a person's "functional limitation," assessed by an occupational therapist or other medical professional who is determined (and paid) by MetroAccess officials to be qualified to judge each applicant's ability to ride public fixed-route transit. In the main, able-bodied medical professionals determine who is eligible and who is denied access to paratransit. They are gatekeepers who lack personal expertise about what it is like to be disabled by an inaccessible environment.

Applicants are judged on their ability to walk or travel up to one-quarter of a mile, travel independently to and from bus stops, identify the correct bus or bus stop to board or get off, get on or off a bus or train using a lift, and ask for and understand instructions to board, ride, and disembark. Disabled people often encounter a well-crafted double-bind in the assessment

process: if assessors determine that applicants' "mobility skills" are adequate, they are deemed able to ride public fixed-route transit, and thus declared ineligible for MetroAccess. But, if assessors decide that applicants lack good mobility skills, they may be denied MetroAccess services, and told to get additional mobility training.

Like hundreds of other disabled workers, I rely on MetroAccess to take me to and from work. I rely on it to get me to school at least twice a week, to out-of-office work-related appointments, to medical appointments, and to social engagements. MetroAccess has caused me to be more than one hour late for work appointments, school, and doctor's appointments more times than I can count, and I have missed some of these obligations altogether when my rides failed to show up at all. During my first semester in school, MetroAccess failed to pick me up after class [even] one time, and I was left stranded in D.C., at ten-thirty at night, in freezing cold weather, with locked school buildings all around me, and with no way home.

Routing has little or no logic. Passengers are forced to share rides that take them in opposite directions than intended. While MetroAccess policy states that passengers are not supposed to be on the van for twenty minutes longer than it would normally take for them to go from one particular destination to another, policy often differs from practice. Once, I rode on the van around the District exactly one hour, for what should have been a twenty-minute ride had we taken a direct route. At the end of that hour, I looked out the window and saw the exact location where I had been picked up. I had been driven around in one big circle, no closer to home than I was before I boarded the van.

Once, when the van came to take me to school, I asked if I would be ride-sharing, and, if so, how long the trip would take. Learning that my shared ride would take an hour and a half—time I didn't have—I asked to be let off the van. The driver refused, saying "You are

already on the van. You must stay on the van until we reach your destination. Go sit down and buckle your seat belt.” I said, “We are still at my house. The van is not moving. Let me off.” Again he refused, and ordered me to sit down. I refused. He radioed the dispatch office to find out what he should do with me. The dispatcher said he would have to check with a supervisor. The minutes ticked by. Finally, after ten minutes, they agreed to let me off the van. Other times, when I protested circuitous routing and unjustifiable amounts of time riding around, drivers scolded me, saying such things as, “Just sit there and be quiet. Your ride costs only \$2.20, so you should be grateful for it.” But MetroAccess is not a charity-based service. I am a taxpayer who contributes to the system, including to its employee salaries. Sometimes, I feel that they treat me as if I were a sack of groceries, as something less than human. My MetroAccess experiences are not unique. When I ride-share with other disabled people, we often swap MetroAccess horror stories.

Because my MetroAccess reservations have “disappeared” from manifests so often, I have learned to check and recheck with the scheduling office to make sure my ride is still listed. Nevertheless, this is no guarantee that the driver will arrive on time, or at all for that matter. Therefore, I made sure to call the reservation and dispatch center earlier in the day to confirm that I was, indeed, on the manifest for a six o’clock pickup to travel into D.C. to meet Mike, Joy, and Len, then to go back home four hours later.

Now it’s six o’clock and the van is not here. Tension vaguely gnaws at the back of my neck, causing the muscles to stiffen and ache. I know that MetroAccess allows itself a fifteen-minute window on either side of my pickup time, so I wait until six-fifteen before I call the office. The dispatcher reassures me that the van is scheduled to pick me up at six p.m. and that it should be there momentarily. By six-thirty my anxiety has given way to frustration. I call the dispatch of-

fice again. A man answers. I say, “My ride was supposed to be here a half an hour ago. Would you please radio the driver?” After placing me on hold for approximately ten minutes, he tells me, “I think we have a mix-up. I’ll call you back in a few minutes.” Twenty minutes later, he calls to say, “We booked you on Fastran (one of the local government’s services), but Fastran doesn’t run on weekends.”

I know that by now my colleagues are expecting me to meet them at the hotel bar. I call their room repeatedly and leave messages. I call the hotel to have them paged at the bar, but there is no paging system there. There is nothing I can do but wait to hear from them. Upset and disappointed, I resign myself to the fact that I will not have my long-awaited, well-planned evening with my British colleagues.

### **May the Light Shine on the Truth Someday**

We have recounted our own personal experiences of interactions of global and local transport systems, and we feel crushed by them. We can (and do) complain vociferously, campaign for the law to be changed, demonstrate on the streets, take our stories to the media, and so on, but complaints are easily managed by large organizations. Laws take a long time to change and while taking to the streets is personally empowering, it will not enable us to go to the next conference, let alone socialize together when we are there.

There are things we need to understand from these crushing experiences. To begin with, it is testament to the global power of the airlines that, even though there is civil rights legislation in both Britain and America, air travel is exempt from those laws. Clearly, the airline industry pays little or no attention to the needs of disabled travelers. As each new generation of aircraft comes off the drawing board, we continue to be designed out, rather than included in. With regard to ground transportation, government subcontracting of public services to for-profit companies dramatically shifts priorities

away from democratic principles of inclusion, and toward the bottom line of profit margins instead.

It is a fact that American civil rights legislation is the most comprehensive and enforceable in the world. Still it fails to ensure that disabled American citizens and their guests can move around their communities when and how they choose. This failure suggests that such legislation promises much more than it delivers. Indeed, we even begin to wonder whether such legislation is nothing more than a confidence trick, actually protecting the interests of the rich and powerful rather than ensuring that the rights of all citizens are actually being properly addressed.

Finally, and most importantly, we would like to return to a point we made earlier. If these are the kinds of everyday experiences that we, as relatively privileged and empowered disabled people, have to endure, what is life really like for those millions of underprivileged and disempowered disabled people who exist in all parts of the world? In talking about our own personal experiences, we hope we have shone some light on the truth of just how far we have to go in order to build a world which fully includes all disabled people.

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## Research Articles

### Learning From Each Other: A Theoretical and Applied Overview of the Relationship Between Disability Studies and Peace Studies

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**Abstract:** This paper is concerned with the importance of dialogue between the interdisciplinary fields of disability studies and peace studies. The considerable potential for learning opportunities arising from understanding this inter-relationship is highlighted through two regional studies. These regional studies focus on the disabling impacts of war and regional conflict and the constructive role of disability studies and peace education in contributing to cultures and structures that enable the non-violent transformation of conflict.

**Key Words:** disability studies, peace studies, interdisciplinary dialogue

\* Editor's Note: This article has been anonymously peer reviewed.

#### Making Connections

This paper invites dialogue between two areas of knowledge that traditionally have not had much direct contact with each other- disability studies and peace and conflict studies. The intention is to help facilitate a process whereby there may be a constructive sharing of ideas, the development of participatory research, and consideration of educational and other pertinent issues. It further develops the profound relevance

of a social view of disability to human and social affairs in this instance in the areas of war, major conflict and the understanding and development of peaceful alternatives.

Given the human and social cost of war and its disabling effects, it may be said that war constitutes a powerful challenge to the moral and social basis of any society. The significantly disabling impacts of war in the production of impairments and the social relations that disable people who have impairments are issues of great relevance to disability studies. Human endeavors to find ways to prevent violence and resolve major conflict is central to peace studies.

In these contexts connecting the emerging area of interdisciplinary scholarship known as disability studies with interdisciplinary scholarship in peace and conflict studies is a most important and pertinent task. The objective of this scholarly alliance, we hope, will be a constructive contribution to new theorizing and practical knowledge of the disabling and enabling dimensions of armed conflict. The focus of such a project could be not only to help achieve a deepened critical understanding of the various *disabling* dimensions of major conflict including war, but to gain a stronger knowledge of how we might attempt to prevent such violence and the resulting impairments and disability.

#### Disability Studies

Disability studies -at least in its more critical discourses- addresses questions and issues about the social, economic, and political dimensions of personal and social experiences of impairment and disablement. Disability studies scholarship seeks ways to illuminate causes and enhance opportunities for access, participation and equity for those affected by impairment, and its disabling consequences. From such a perspective disability refers to the disadvantage and discrimination experienced by people who have impairments (Davis, 1997; Finkelstein, 1980; Morris, 1991; Oliver, 1996). This new and re-concep-



tualized notion of disability moves beyond, for example, the oversimplifications of conventional medical interpretative frames and the oppressive blandishments of “biological fixes,” including the dangers of new eugenics thinking (Oliver, 1990; Meekosha, 1998; Barnes, Mercer & Shakespeare, 1999; Clear, 1999). Barnes (2005) highlights the holistic dimension of a social model of disability when he says that it is “a holistic approach that explains specific problems experienced by disabled people in terms of the totality of disabling environments and cultures” (p. 7). War and major conflict, as this current paper discusses, causes and results in significantly disabling environments and cultures (Clear & Hutchinson, 2004/2005).

### **Peace and Conflict Studies**

One of the key concerns of inquiry in the field of peace and conflict studies is with critical learning about the causes and disabling consequences of direct and indirect forms of violence, whether they be at local, regional or global levels. The field is also very much concerned with the search for practical knowledge about alternatives (Hutchinson, 1996; Reyhler & Paffenholz eds, 2001; Francis, 2002; Galtung, Jacobsen & Frithjof Brand-Jacobsen, 2002, French, Gardner & Assadourian, 2005).

Such practical knowledge includes building improved understandings, insights and skills as to how to transform conflicts non-violently rather than through armed conflict. There is, moreover, a related interest in exploring ways of creating structures and cultures of peace rather than war. Particular attention is given to issues of applied foresight, responsible citizenship and applied ethics, especially as they relate to opportunities for meaningful choices and democratic participation in actively resisting impaired, violent futures for our children and their children (Hutchinson, 1996; Machel, 2001; Boyden, 2002; Boulding, 2004).

### **How War and Conflict Disable**

War, regional conflict and its disabling impacts are costly to individuals, families, communities and wider regional interests. Beyond the pain, distress and dislocation experienced, war often represents loss of human development and potential, and opportunities for full and equal participation to all levels of social and economic life of the community. War and violent conflict are significant factors causing impairment and the WHO, UNICEF, UNHCR and other UN surveys have documented, amongst other things, the role of violations of human rights and of humanitarian law as causes of disability. The numbers globally are very considerable. Presently, there are some 200,000 child soldiers. In the twentieth century, more than 100 million people were slaughtered in wars. Over 90 per cent were civilians. Although horrifying in themselves, such casualty figures represent only a fraction of the suffering caused by armed conflict (Harknett, 2000; Marcel, 2001; Cheldelin, Druckman & Fast, 2003; Hinde & Rotblat, 2003).

More specifically, causes of impairments from war and violent conflict include: torture and other attacks on the physical or psychological integrity of persons, malnutrition, lack of sanitation and of proper medical care, environmental destruction, disruption and deprivation of educational provision, and underdevelopment in general. Specifically, resulting conditions may include: amputations, bullet wounds, gynecological and other impacts of rape, starvation, poor nutrition and consequences, displacement (refugees), and psychological and social impacts such as, post-traumatic stress, gendered violence, and many forms of discrimination. The UN emphasizes that many disabled persons belong to vulnerable groups, such as children, immigrants and refugees (UNICEF, 1996; Harknett, 2000; Blaser, 2002).

Whilst it may be difficult to countenance, we are currently in the midst of the Internation-

al Decade for a Culture of Peace and Non-violence for the Children of the World. In passing a resolution in favor of such a decade, among other things the UN General Assembly highlighted the need for applied research concerned with substantially lessening, preventing or transcending such impairment, harm and suffering. In addition they urged research to better understand the enormously disabling harm and suffering that is caused to children and youth by war and other forms of violence (see UN General Assembly Resolution, 55<sup>th</sup> plenary meeting, 19 November, 1998, A/RES/53/25).

It is the intent in this paper to explore interdisciplinary relations between disability studies and peace and conflict studies and indicate practical links by highlighting some substantive issues that can be demonstrated through discussion of regional studies of major conflict.

### **Pertinent Studies of Regional Conflict**

The theorized relations of the powerful and contemporary knowledge of disability studies and peace studies may be demonstrated in regional studies of conflict.

The regional studies outlined here are an introductory way of asserting that much can be learnt about disability and also peace studies by drawing out interdisciplinary connections. For the purposes of our argument this is a relatively detailed historical overview and rationale of the regional conflicts. We position the regional studies as exemplars of how the discussion of relevant literature on a topic can highlight and demonstrate powerful disability and peace studies links. It may also lay the groundwork for the conduct of further study.

### **Bougainville Regional Conflict**

Bougainville is the largest island to the north of Australia and part of the Solomon Islands archipelago, just 8 kilometers from the arbitrary sea border of the independent state of the Solomon Islands. It is some 700 kilometers east of Papua New Guinea (PNG) and a similar

distance from Australia's northern border. Until September 1975, when it was incorporated into an independent Papua New Guinea, it had been subject to Australian colonial rule. It is clear that Bougainvilleans themselves did not accept either the colonial rule or the incorporation into PNG and identify ethnically and culturally with the Solomon Islands. During the 1970s, demands for a referendum on self-determination were denied to Bougainville (Havini & Havini, 1995).

More recently, Australia has played an important part in bringing some settlement and peace to the area. This follows 10 years of civil war between the PNG defense forces and the Bougainville Revolutionary Army (BRA) in a costly struggle for independence that has led to some 7,500 deaths and uncounted injuries and impairments. This struggle was most directly precipitated by the operation and mining of Rio Tinto's Panguna valley mine (Regan, 2001).

In 1965, Conzinc Rio Tinto of Australia located very large deposits of copper-ore in the Panguna valley and in order for development to proceed, customary title to the land was denied to local landowners. Commercial production began in 1972 through Conzinc Rio Tinto's subsidiary Bougainville Copper Limited (BCL). The mining activities of BCL resulted in the major environmental, social and political dislocation of Bougainville. One University of PNG academic who was Head of Environmental Science said of the Panguna project that it was "an economic godsend-and an environmental disaster."

The Bougainville Peace Agreement was signed at Arawa in Bougainville on 30, August, 2001. This is a comprehensive agreement that brings together the three agreements reached over the previous eight months that relate to the issue of a referendum to determine the eventual political future of Bougainville, a weapons disposal plan, and arrangements for autonomy. In December 2001, a weapons disposal ceremony was held at Torokina (Regan, 2001). Also, Bou-

gainville ex-combatants and National Government officials agreed on a budget and schedule for weapons disposal awareness activities (Havini & Havini, 1995).

Clearly, Bougainville is an important part of the Pacific region and Australia's past and present history is closely linked with it. Australia has significant strategic, humanitarian and peace-related interests in Bougainville's social and economic development.

### **Cambodian Regional Conflict**

Crucial issues as to Australia's relations with the peoples, cultures and societies of the East Asia-Pacific region are likely to become even more important in the twentieth-first century than they were in the last. Geographically, Australia is very much part of the area. Economically, there are strong links. Australia, too, has had a significant history of military engagement in the region. The latter includes the Boxer Rebellion in China, the war in the Pacific, the Korean War, the stationing of Australian troops at Butterworth in the Malay peninsula, the Vietnam war, military assistance to the Lon Nol regime in Cambodia, East Timor peacekeeping operations, and the war in Afghanistan.

Culturally and with respect to immigration, refugee and development assistance policies, the story is more complex. There are important considerations for what it may mean for Australia's evolving identity, sense of being "a responsible global citizen" and long-term interests. In a post-September 11 world and in the light of recent Australian government policy and actions to refuse entry to asylum seekers, these dilemmas and challenges are necessarily even more pronounced.

At the time of Australian federation (1901), "the white Australia policy" was sacred text. National identity meant "one people, one nation, one race." One of the first serious tests of the abandonment of "the white Australia policy" came with the Indochinese "boat people" fleeing

the armed conflict and destruction in Vietnam and Cambodia (Mares, 2001; Jupp, 2002).

During the Pol Pot years, an estimated 1.7 million people lost their lives in "the killing fields" of Cambodia. This amounted to almost one in four of the Cambodian population. Many others were injured, impaired or scarred by the experience. Large quantities of mines and other unexploded ordinance remain in the Cambodian countryside.

The UN and also others report that the main injuries that result are loss of limbs and injuries caused by bullet wounds. Also significant is gynecological and other impacts of rape, starvation and poor nutrition. The consequences impact not only the ability of affected individuals to participate in the activities of everyday life such as schooling and employment but also on the very physical and social infrastructure that would facilitate their rehabilitation and participation. Of course this includes basic human and social rights for equal inclusion in the life of the community (UNICEF, 1996; Harknett, 2000; Blaser, 2002).

Even before Pol Pot, up to several hundred thousand Cambodian men, women and children had lost their lives as the war in Vietnam spread across the Cambodian border. From 1972 to 1973, for example, the quantity of bombs dropped on Cambodia totaled well in excess of three times that dropped on Japan during World War Two. Deposed Cambodian leader Prince Sihanouk was to later claim that Richard Nixon and Henry Kissinger had in a sense created the Khmer Rouge by the expansion of the war into Cambodia. Whatever the reasons, there have been long term consequences for a tortured country (Glover, 1999; Robertson, 2002).

While Australia had joined the USA in the war in Vietnam as a matter of perceived national interest, this had not enjoyed uncritical support at home. It is against this background that Australia was to come to later play a significant role in the Cambodian peace process. The then

Australian Foreign Minister, Gareth Evans was to become actively involved in this process, including the establishment of a UN transitional, peacekeeping authority. Skilful middle power diplomacy had played a valuable part in this development (Berry, 1999; ABC, 2002).

### **Broader Relevant Literature**

Linked to a better understanding of the global context of such regional studies, there are important and relevant data-collection programs by the UN, WHO, UNHCR, UNICEF and other international humanitarian and development agencies. This data collection is done as an adjunct to their work in regional communities affected by war and structural violence around the world. Latest UN estimates put the number of people who suffer chronic hunger at 850 million. Many of these are in areas devastated by years of armed conflict, such as Afghanistan and Guatemala, and in societies, such as North Korea, which lavish expenditure on military programs at a damaging cost to meeting basic human needs. More generally, there are enormous opportunity costs in the 1 trillion dollars spent each year on armaments and military forces; costs that represent lost opportunities for other health giving expenditures. Over half of the world's military budget is paid for by the United States. In a recent UN report on the state of world food security/insecurity, the largely invisible costs of skewing the notion of "security" to narrowly military formulations and dollar demands is brought out. "Bluntly stated, the problem is not so much a lack of food as a lack of political will" (FAO, 2003).

In addition to such studies, there is a range of other relevant literature that includes discussions of post traumatic stress disorder as it relates to war and violent conflict (Sack, Clarke & Seeley, 1995). The latter literature raises important issues for peace educators and others engaged with peacebuilding. As part of any meaningful reconciliation endeavours in societies affected

by the damaging legacies of violent conflict, whether on mind, body or social infrastructure, important educational and other considerations are raised (Hayner, 2001; Salomon & Nevo, 2002). These often involve the need for peacebuilding amongst previously warring groups, rehabilitation of individuals who are impaired by war and likely to be disabled in communities that are built as if there are no impairments. These same communities, themselves will require rebuilding physically and socially (Lederach, 1997; Salomon & Nevo, 2002).

### **Emergent Themes of the Literature and Regional Studies**

Through regional studies we should be able to get a better understanding not only of the disabling affects of war and other forms of violence on communities and families, but also the potential ways of creating more enabling, less violent futures for people affected by war and violence.

Beyond drawing together this literature, we think critical understandings and insights can be gained by asking the following questions in relation to the regional studies that are overviewed in this paper. The questions themselves reveal interesting and pertinent dimensions of the interrelationships of disability studies and peace studies. Specifically we want to ask:

- What are the disabling consequences (physical, social, gender-related, educational) of war or armed conflict in this region?
- What human rights and international law is relevant in the aftermath of conflict and how has it been experienced in practice?
- How may constructive peace-building initiatives be undertaken to reintegrate/empower those affected/disabled by war or armed conflict in the region?
- What community strategies/techniques/processes are most likely to contribute

to enabling cultures of peace and inclusion for ex-combatants in the region?

- What are the possible lessons from this regional situation for practical peace-building initiatives among those affected by the aftermath of violent conflict or war elsewhere in the world? (Clear & Hutchinson, 2004/2005)

Literature particularly relevant to such regional studies highlights the potential for mutual learning between the fields of disability studies and peace and conflict studies. Existing studies are still relatively small but nonetheless important. They include, for example, studies of the experiences of survivors and their traumas from situations of armed conflict (DePaul, 1997), the prevalence of psychopathology in adolescents from refugee families (eg Tousignant, Habimana, Biron, Malo, Sidoli-leblanc & Bendris, 1999), and genocide and disability (eg Blaser, 2000). There is also some important analysis of approaches and programs for intervention with children and youth affected by armed conflict (Crisp, Talbot & Cillopone, 2001; Canadian International Development Agency, 2002).

### **Towards a Disability and Peace Discourse**

The matters raised through these complementary regional studies are varied and are likely to have significant practical and applied dimensions. They include issues of appropriate humanitarian action and development assistance, resilience, trust-building and meaningful reconciliation, conflict resolution skills development, and the encouragement of educational and other opportunities and choices for active participation in processes for creating more enabling, inclusive and peaceful futures. Such practical efforts would make central a rehabilitation focus that is not only about the repair and restoration of individually impaired bodies, but the rehabilitation of the social infrastructure and social rights that will ensure that individu-

als can take an active part in communities that are themselves just and healthy.

The overall benefits, constructive lessons and wider applicability of such interdisciplinary conceptualizing could be multiple. Specifically, with each regional study it is possible to focus and articulate achieving benefits in a range of areas such as those briefly discussed below. In important ways, such benefits are likely to be complementary in deepening both understanding and exploring alternative pathways. We see them as involving directly related matters of civic or socially engaged foresight, humanitarian benefit and other practical rehabilitative, social and educational outcomes (Hutchinson, 1996; Reyhler & Paffenholz, 2001; Francis, 2002). They are inextricably bound with greater understanding of the disability and peace issues that we have outlined. Moreover, they expose disability and rehabilitation as central social constructs for defining and building peaceful futures non-violently.

These particular regional studies suggest very important issues concerning youth, disability and peace building. In terms of the exploration and conceptualizing of disability studies and peace studies as potentially something greater than the sum of their separate meanings, we believe this presents particular issues for defining more enabling futures. This is not a singular view of the future but rather an opening up of dialogue on alternative futures (Galtung, Jacobsen & Frithjof Brand-Jacobsen, 2002; Hicks, 2002; Slaughter, 2004).

In the regional study involving Bougainville, a central issue of disability and peace is the effects of recent armed conflict and violence-enculturation upon young ex-combatants. Many young Bougainvillean men have been psychologically and physically impaired by extended periods in armed conflict. Reintegration and inclusion in communities that are themselves disabled by conflict, will require significant and sustained rehabilitative effort.

The Cambodian regional study looks at the longer term, intergenerational effects of the legacy of war in post-conflict situations. In this case, the emphasis is on some second-generation social, economic and educational implications. The children of displaced persons or refugees who have settled in Australia from Cambodia offer an important example of the opportunity to work collaboratively in seeking to better understand such complex and culturally sensitive issues. In each case, there is a particular interest in the potential for greater inclusion and participation of those people disabled by war and regional conflict and peace-related, community-building initiatives.

This conceptualizing must finally extend to regional and global questions of power relations that maintain profound patterns of disabling social and economic relations. This refers to a “structural violence” that is deeply implicated in war and regional conflict and their disabling impacts (Boulding, 1990; Calder, 2002; Monbiot, 2003).

There is also an important related dimension in terms of Australia’s negotiation of its place and identity in the Pacific region and as part of the international community over coming decades. Such negotiation includes issues of disability and inclusiveness, immigration, multiculturalism, education for human rights, conflict resolution, literacy, development assistance to low-income countries, and more broadly Australia’s responsibilities under international law and as a member of the United Nations. In relation to the particular regional conflicts described in this paper, there are important issues of regional and global citizenship and commitment to an international legal framework that impacts amongst other things, the human rights status and citizenship rights of disabled people (Boulding, 1990; Calder, 2002; Held, 2000; Monbiot, 2003).

## Some Educational and Other Implications

The regional studies looked at through the interdisciplinary lens we have described suggest several key areas for new knowledge and development. Among these are:

- *The building of enduring partnerships* for research, education, youth and community policy development initiatives and projects amongst relevant local, national and international organizations.
- *Documented knowledge* relating to the causes and impacts of impairments that have resulted from the conflict in Bougainville and Cambodia involving individuals, families and communities. This will include relevant examples of community peace building and enabling-futures initiatives and projects.
- *Educational curriculum and resources* for educational development, policy and legal frameworks, and community building. Consistent with a collaborative and inclusive design and methodological approach, any such recommendations and resource development could be integrally linked to negotiated processes and outcomes with participants in local communities, including disabled people.

These resources could be suitable for university, Community College and senior secondary levels, professional development and organizational in-services. This could inform the training and preparation of personnel for work with local and international communities that is cross-culturally sensitive, conscious of innovative theory and practice in areas such as peace education and human rights education. It could be informed by the social demands of access and participation and human rights requirements of people with disabilities.

- *Personnel preparation* for local citizen-

ship responsibilities and global citizenship to provide the knowledge and skills for building peaceful futures, which includes thorough-going understanding of the important role of inclusive and accessible environments in building peace.

Some of the educational and other potential benefits of applied scholarship may be understood at several levels. In terms of international relations, there are critical policy issues about the viability of current patterns and approaches to secure peace. There are key future-related issues about whether the conventional paradigm of “working for peace by preparing for war” and heavy reliance on responding to perceived threats to security by military means will continue to prevail or whether alternative, more enabling (less disabling) pathways may emerge and be strengthened. This is especially so when considering the legacies of armed conflict and structural violence on many young people, and what these disabling legacies may mean for the future if left unresolved.

At the level of multi-cultural and community relations, there are perhaps significant lessons to be derived in terms of enabling rather than disabling notions of identity and citizenship. There are also lessons for building ties of friendship rather than cultural stereotyping, hatred and xenophobic barriers. Such matters are, for example, very much a part of contemporary discussions in Australia about its relations with its northern neighbors. These are discussions that are also occurring in many other parts of the world.

At the level of socially engaged, critical inquiry, such knowledge development seeks to get beyond tight disciplinary and epistemological boundaries. It offers opportunities for the furthering of constructive dialogue among communities of learners rather than reinforcing established disciplinary territorialities. It welcomes multi-cultural voices rather than mono-

logue and cultural rigidity. There is, therefore, an invitation to humility and openness, while acknowledging the likely challenges and crucial importance of a strong ethical approach in working for enabling, decolonizing methods.

Such critical and applied endeavors actively open up questions of a cross-disciplinary character as to whether, for example, the knowledge traditions of disability studies and peace and conflict studies may have something to offer each other. It also critically reflects on their possible joint contribution to our better understandings of issues such as the practicalities of building cultures and structures that are more inclusive, enabling and peaceful.

### **Future Developments**

The literature and regional overviews serve as a basis for a more fully developed dialogue of the issues. We expect future collaborations in this area to:

- Assist in developing a new interdisciplinary perspective with significant potential for contributing to theoretical and conceptual aspects of disability and peace scholarship.
- Bring together the research and development interests of hitherto largely separate knowledge domains to address significant social questions and actions associated with disability that results from armed conflict, militarization and the legacy of war.
- Seek to understand social systems that disable and that also enable, rather than assume disability is only an individual human problem. Such a focus would bring to this discussion the valuable lens of disability studies and the broad distinction between impairment and disability. We see this as a relative rather than an absolute distinction and emphasize the interrelationship of the individual and the social, impairment and disability.

- Focus on young people and others affected by war in ways that seek to transcend “victimology accounts” and “problem youth” stereotypes.
- Endeavor to make important links between the local and the global in matters of disability, war and war prevention, including issues of humanitarian concern, human rights and responsible global citizenship.
- Attach considerable significance to a creative futures and applied foresight dimension in which initiatives, actions and efforts, especially by young people, are explored for averting war, lessening the damaging consequences of armed conflict, and for building accessible, just, peaceful and enabling futures.

In summary, we think these developments should lead to not only a better understanding of the disabling effects of war and other forms of violence, but also to potential ways of creating more enabling, less violent futures for those people disabled by war. The regional studies could extend to include critical questions about the social and environmental dimensions that are central to a social model of disability and to effective peace-making and peace-building. This could include policy considerations and the role of education both formal and informal. We believe that these will be critical to the re-integration and citizenship interests of both the individuals concerned and the communities of which they are or might be a part. It is essential both for credibility and for basic justice that this work includes the active participation of disabled people themselves.

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## **RASEM Squared: Assisting Students in their Transition to the STEM Workforce**

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**Abstract:** RASEM Squared works to increase the number of people with disabilities pursuing careers in science, technology, engineering, and mathematics (STEM) fields. To accomplish this goal, it provides funding directly to students to support their college education and to educators who accommodate students with disabilities in their STEM curricula. This paper describes several projects that illustrate RASEM Squared's activities, and identifies six major issues that have arisen in its work. These issues involve student self-disclosure, transition from supports under the *Individuals with Disabilities Education Act* (IDEA) to those under the *American with Disabilities Act* (ADA), training of special education and science education teachers, use of assistive technology (AT) devices, compatibility of software and hardware, and links between services.

**Key Words:** transition, STEM, careers

### **Introduction**

People with disabilities are natural problem-solvers. Each day, they improvise on-the-spot solutions to human and physical barriers. Honed in such a way, their skills and talents are prepared for tackling complex high-tech problems requiring a team-oriented approach for solution and implementation. Yet, persons with disabilities are underrepresented in science, technology, engineering, and mathematics (STEM) fields. Currently, persons with disabilities are 14 percent of all employed persons and five percent of employed scientists and engineers (National Science Foundation, 1999). This is problem-

atic since advances in technology and the need for highly trained military personnel to operate high-tech equipment presently strain the demands on an already depleted workforce. For example, Minor (2003) has observed:

“[While] women, minorities and people with disabilities have come to represent a significant proportion of the labor force, they continue to be underrepresented in the computer science arena.... The full utilization of our nation’s human resources through continued progress in achieving diversity in information systems is considered by many policy makers to be a vital factor in achieving improved international competitiveness in and alleviating the staffing shortage crisis.”

### **RASEM Squared**

As suggested by the President’s Commission on Excellence in Special Education (2002), all post-secondary institutions receiving federal funding need to be held accountable for helping students with disabilities complete a high quality post-secondary education. While bringing persons with disabilities into the STEM workforce appears to be an appropriate application of this priority, the question remains, “Has higher education begun to succeed in this endeavor?” From our perspective as an organization established to increase the number of students with disabilities who pursue courses and careers in STEM, the answer is *yes*.

The Regional Alliance for Science, Engineering, and Mathematics (RASEM) Squared is a program primarily funded by the National Science Foundation (NSF) and administered from the New Mexico State University College of Engineering in Las Cruces. RASEM Squared encompasses a service area that includes all of New Mexico; the Navajo Nation of eastern Arizona and western New Mexico; and far west Texas from Oklahoma to the Rio Grande and from El Paso to the Pecos River. The Alliance is composed of 67 partners consisting of 19 two-

year colleges, one of them in Texas; eight four-year colleges and universities, two of them in Texas; 15 regional education cooperatives, six of them in Texas; two national research laboratories; nine NSF regional sister organizations, and 14 governmental education agencies, including advocacy and service provider organizations.

The primary goal of RASEM Squared is to increase the number of students with disabilities who graduate with baccalaureate degrees leading directly to graduate training or to employment in their desired field. Toward that goal, 37 RASEM-sponsored students with disabilities have graduated from NMSU and its partner institutions to STEM careers since 1995. An additional 77 students are currently enrolled at NMSU and partner institutions in STEM undergraduate and graduate training programs. In recognition of this work at the college level, RASEM Squared has been identified as first in the Nation each year since 2002 by the American Association for the Advancement of Science’s *Entry Point* program in securing co-op positions, summer employment and career employment opportunities for students with disabilities. At the pre-college level, 816 New Mexico and Far West Texas K-12 students are currently engaged in RASEM Squared-funded science education environments.

To help accomplish its primary goal, RASEM solicits and funds one-year projects varying in amounts from \$2,500 to \$10,000. Requests for proposals (RFPs) are provided to potential grantees with awards based upon adherence to RFP guidelines and the potential for stimulating interest in STEM careers among students with disabilities. Programs supported by RASEM address the following six initiatives:

- Hands-on science experiences for pre-college students
- Formal research experiences for pre- and post-baccalaureate students
- Preparation of faculty for full partici-

**Table 1: Major Program Components**

<b>Component</b>	<b>Purpose &amp; Funding Level</b>	<b>Example of Funded Project</b>
<b>Teacher Outreach Projects (TOP)</b>	To provide K-12 teachers an opportunity to obtain mini-grants for projects that include students with disabilities in innovative, hands-activities in STEM curricula. One-year projects are funded for a maximum of \$2,500.	<i>Get Wet</i> was a funded TOP Project at Gadsden High School in Anthony, New Mexico. The Project Director was a chemistry teacher who intended to provide her students with information related to water quality and its impact on the community. Participating students studied mock newspaper articles describing dead fish in a local river, collected water samples on field trips, tested the samples for purity and softened water in their lab, and participated in a simulated town council meeting. Twenty-five students representing all categories of exceptionalities were recruited for the project through their science classes.
<b>Partner Projects</b>	Partner Projects are funded for one year at a maximum of \$10,000. Funding is intended to enhance the opportunities and involvement of students with disabilities in the STEM areas. Partner Projects address the same initiatives as TOP Projects but require a higher funding level due to their scope.	<i>Science, Engineering and Math: Introduction to Academics (SEMIA)</i> is a Partner Project conducted annually at the University of Texas, El Paso (UTEP). This project brings local area high school students with disabilities to the UTEP campus for a three-week summer orientation program that provides guidance and counseling, information and referral, and training. Major foci are on computer skills, science laboratory and mathematics experiences, and career exploration coupled with self-management skills.
<b>Mentor Projects</b>	Merit-based mentorships or stipends are awarded to qualified students who are enrolled fulltime at NMSU or partner higher education institutions, qualify as a student with a disability, are a STEM major, and carry a 3.0 plus GPA. The Mentor program provides a \$1,200 per calendar year award. For students whose GPAs fall between 2.0 and 3.0, a \$750 stipend is available	The major expectation for Mentors is that they succeed in their post-secondary academic coursework. However, Mentors are often called upon to assist in programs such as the <i>Robot Project</i> that engages up to 30 elementary through high school students for two days in an inclusive environment. Participants learn basic electronic concepts, build robots from kits and race them to see which team was most successful in applying newly learned knowledge and skills.

pation of students with disabilities in STEM curricula

- Bridge programs between academic levels
- Mentoring by successful STEM professionals and STEM students with disabilities
- Securing co-op, summer internships, and professional employment.

Table 1 outlines the three major components of RASEM Squared. All projects receiving support from RASEM Squared must address at least one of the six initiatives listed above.

### Transition Issues

RASEM Squared staff members have encountered several persistent problems while assisting students with disabilities make the transition to STEM careers. When the problems have arisen, staff members have attempted to deal with them on a case-by-case basis. The list that follows categorizes problem areas, describes specific issues connected with those areas, and suggests strategies for others at the pre-college or college level who may attempt to assist students in the transition process.

### Student Self-Disclosure

Resources are available on most college campuses to assist students with their academic pursuits. The problem is however, students are often hesitant to disclose their disability in order to obtain needed resources. Twenty-year-old Ray (not his real name) left the university with a 2.8 GPA after two semesters and one summer session. Ray understood the material and was observed to apply it well but felt *burned out* from working three times as hard (his estimate) as his fellow students. Ray chose not to disclose his learning disability in order to obtain available resources such as a reader or notetaker which *were* available on campus and could have been used with his computer to cut down the time required to prepare written assignments.

### *Suggested Strategies for Assistance:*

- Instill in students the attitude that they (not the faculty) are in control of their destiny at the college level. That, *yes*, a negative image of disabilities persists at the college level, but that pride associated with success may only come about by taking advantage of the resources made available through disclosure.

### Transition Between IDEA and ADA Support

Under the *Individuals with Disabilities Education Act* (IDEA) (American Youth Policy Forum, 2001), the school takes the lead in seeing that K-12 students promptly receive free services to meet their unique needs including non-academic needs. This is not true under the *Americans with Disabilities Act* (ADA) at the college level where students must take the lead in securing services and services are limited to academic assistance.

### *Suggested Strategies for Assistance:*

- Provide information to students and their parents regarding the transition from IDEA and ADA. Make sure that students understand that the burden of responsibility for obtaining resources shifts from school personnel to the student upon entry into post-secondary programs.
- A training course in transition is currently being developed by RASEM Squared. It is a semester-long 3-credit course for mid-school students and their parents and teachers designed to avoid the pitfalls of transition between IDEA and ADA. RASEM is currently seeking support to teach the course via interactive television.

## Teacher Training

At present, science education and special education teachers have very little training in common. Thus, while special education teachers may understand district, state and federal special education requirements such as written transition plans for students with disabilities ages 14+, science educators may not. Similarly, science educators may understand Newton's laws of motion but not know how to modify their instruction to teach these concepts to students with disabilities who may have interest and potential for STEM careers.

### *Suggested Strategies for Assistance:*

- Take action to get pre-college teachers and college faculty members to increase communication across disciplines in relation to involvement of students with disabilities in STEM areas.
- RASEM Squared has addressed this issue on a local level by funding a series of workshops in Farmington, New Mexico. These workshops have brought science and special education teachers together to discuss important issues including disclosure and IDEA-ADA transition, and the importance of increasing the number of students with disabilities in STEM fields.

## Assistive Technology (AT)

Although AT devices are available including text-to-voice software for students with visual impairments, many teachers feel unprepared to integrate such technology into the subjects they teach. According to the National Science Board (2002), "Only one-third of teachers reported feeling well prepared or very well prepared to use computers or the internet for classroom instruction...For many instructional activities, teachers who reported feeling better prepared to use technology were generally more likely to use it..."

### *Suggested Strategies for Assistance:*

- Assist teachers in obtaining available training in AT.
- RASEM Squared has developed AT workshops for science and special education teachers to obtain training in new and unfamiliar AT devices. This graduate-credit workshop requires development of a curriculum project that includes use of AT in classroom activities.

## Hardware and Software Compatibility

Today's college campuses provide an impressive array of computer stations and software available for students to do homework and research. However, when moving from one department's computer lab to another, students encounter a lack of compatibility. For example, word processing software may be different in terms of model and/or version. As a result, it is difficult for students with disabilities to move from machine to machine because AT devices are not compatible and/or formatting characteristics are lost in the process.

### *Suggested Strategies for Assistance:*

- Work to assure compatibility across environments for students who must rely on assistive technology.
- RASEM Squared is collaborating with the NMSU College of Engineering, the New Mexico Division of Vocational Rehabilitation (DVR), and the NMSU Office of Facilities Services to create a model system that will allow students to move across campus environments with a minimum of downtime needed to employ their AT devices.

## Linkage Between Services

Many services exist on modern post-secondary campuses whose mission is to assist students in their academic work and career preparation. Two typical services at NMSU are the Placement and Careers Office and Special Student Services. The problem is that these services may not overlap on a case-by-case basis when neces-

sary. For example, when a placement and careers office is facilitating campus-based employer interviews, it may not be aware of the accommodation needs of students with disabilities already known to special student service personnel.

*Suggested Strategies for Assistance:*

- Work to get various offices and agencies to work together to identify overlapping, redundant, or missing efforts used to reach their mission.
- RASEM Squared has joined in a partnership across several NMSU offices and IBM to create a streamlined process for persons with disabilities engaged in the interviewing/hiring process.

### **Conclusions**

The greatest difficulties faced by students with disabilities as they enter the area of higher education are:

- The need to disclose in order to receive assistance;
- Ignorance of transition issues between IDEA and ADA;
- Special education teachers, general education and science teachers who are unprepared to teach outside of their topic areas;
- Teachers who are unprepared to integrate such technology into the subjects they teach;
- Hardware and software incompatibility between departments, and
- Lack of overlapping services between departments.

The solutions rely on the students' own initiative, which must be nurtured and encouraged by organizations and services designed to provide such accommodations, and the re-training of teachers both at the secondary and post-secondary levels of education. The result will be

students who learn how to live independently and to have careers as high-tech professionals. In addition, resources that promptly and efficiently respond to students' needs will also create an environment that supports the goals of transition. Ultimately, the workforce will be enlivened and enriched by a new wave of natural-born problem solvers who are currently underrepresented.

Readers from the RASEM Squared catchment area are encouraged to contact project representatives at <<http://rasem.nmsu.edu>> or by calling 1-888-646-6051 to obtain information about funding of Partner and TOP projects as well as mentorships and/or stipends for college students with disabilities majoring in STEM fields.

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# Learning Disabilities, the Missing Discussion in Disability Studies: Is There a Possibility for Alliance?

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**Abstract:** We propose an alliance between disability studies (DS) and the field of learning disabilities (LD); an alliance based on the need for shared research ethics and a critique of contemporary educational practices that perpetuate misunderstandings and marginalization of disabled students. The positivist thinking that has permeated both research and instruction in LD has resulted in significant minority overrepresentation. Not only could LD benefit from DS social analyses and humanities scholarship, but DS could become a more inclusive, more representative discipline.

**Key Words:** learning disabilities, disability studies, impairment

\* Editor's Note: This article was anonymously peer reviewed.

\* Authors' Note: We chose to use the term "disabled students," rather than person-first language for two reasons. First, it is the preferred term of many disabled persons and disability rights activists<sup>1</sup> (Corker & Shakespeare, 2002; Erevelles, 2000; Gallagher, 2001, 2004; Kudlick, 2003; Linton, 1998; Longmore, 2003; Mitchell & Snyder, 2000; and Peters, 2002). Second, it shifts the focus from personal "impairment" to society's disabling practices.

*I propose an intellectual alliance between whiteness studies and disability studies in order to accentuate the underlying invisibility of normative whiteness and able-ness ideologies. These structures are at the core of Western culture, and yet remain unnoticed, un-observed. Without turning our cultural gaze on them –without scrutinizing and*

*inspecting their borders –these ideologies will continue to oppress and obfuscate, exclude and excise, human communities that have been placed not just outside the margins, but off the page (Smith, 2004, p. 13).*

In this essay, we propose an intellectual alliance merging learning disabilities (LD) and disability studies (DS) discourses. Our project is similar to that of Smith in that we also use a DS lens to shed light on and accentuate the underlying invisibility of the normative standards and able-ness ideologies, not of whiteness per se (although it is certainly implicated), but of our lock-step, largely reductionist educational system. These structures—normative standards and able-ness ideologies—are at the core of Western culture as it is embodied in the white, male, Anglo-Saxon, Eurocentric standards of behavior and curriculum that under gird both historical and contemporary public education in the U. S. Up to 12% of the school-aged population is typically and legally labeled as disabled for funding purposes (based on the assumption this population requires a more expensive "special" education) and about 40% of those students are labeled as LD (Hehir, 2002). Moreover, many of these students are from so-called minority groups who have been marginalized historically by our society and hence, our schools (Losen & Orfield, 2002). Across all high incidence disability categories—LD, Emotional and Behavior Disorders (EBD), and Mental Retardation (MR), for example — we find minorities are overrepresented (Zhang & Katsiyannis, 2002) to varying degrees.<sup>2</sup> To those who would benefit from noticing such discrepancies and particularly to those whose children profit from the current state of affairs (see Brantlinger, 2003), the disparities and injustices appear to be inevitable or remain unnoticed and un-observed. Without turning our cultural gaze on these normative standards and able-ness ideologies—without "scrutinizing and inspecting their borders"—they will "continue to oppress and obfuscate, exclude and excise, human communities that

have been placed not just outside the margins, but off the page” (Smith, 2004, p.13).

### **Why the Disengagement?**

There is an ever-growing group of inclusive educators (including LD scholars) who embrace principles of DS and who participate in the Disability Studies in Education Special Interest Group of the American Educational Research Association. Nevertheless, as things stand, DS is typically disengaged from LD—and vice versa. It is difficult, for example, to find references to LD in the mainstream DS literature in the social sciences or the humanities, and it is equally rare to find references to DS in the mainstream LD literature. However, the two fields have much in common. When we heed Smith’s (2004) call to look closely at the way Eurocentric maleness operates to subjugate disabled people through disability-centered technologies promoted by capitalism, we see the LD category as one of those technologies. Moreover, whiteness-bias as it intersects with disability prejudice is common to both our educational concerns and those of the larger community of DS scholars. Because he mentions special education students who are affected by minority overrepresentation, Smith (2004) at least gives a silent nod to the impact and importance of LD, as the largest of those special education categories within the sphere of DS concerns.

It seems, then, that there is a continued silence around LD as a *specific* societal and institutional concern, rather than as one aspect of special education. Perhaps this is because DS scholars are perceived as “outsiders” whose distant gaze perceives the field of special education as one entity. Or perhaps there is a general aversion to sorting and labeling students. DS scholars may also have overlooked or avoided the LD question because of their preoccupation with their own concerns—many of the influential scholars in the field have physical or sensory disabilities, their work is centered in the humani-

ties and the social sciences, and the historical preoccupations that accompanied the Disability Rights Movement were with more visibly embodied differences (Fleischer & Zames, 2001). Another reason emerges from sad memories or even disdain for the personal experiences of people with disabilities within special education and a concomitant fear that this new DS discipline may become tainted by association with an educational discourse. Moreover, some DS scholars may also want distance from the intellectually challenged “other” (i.e., a person labeled LD) and thus buy into the disability hierarchy favoring the physical over cognitive differences (see Mitchell & Snyder, 2000).<sup>3</sup> We could speculate *ad infinitum*.

But there is one reason we would bet on: The absence of LD in the DS literature is because many suspect that LD is school-generated and not a *real disability* at all—the opposite of the assumption made by most LD scholars (we shall deal with this issue later). We, however, consider the “realness” of LD as being precisely and strategically a product of our perceptions as they are shaped by cultural needs and discursive practices. There is little doubt that we *make LD exist* to the extent that *we need it to or think it does*, which goes to the heart of one of the major DS premises that disability per se is a social construction.

### **What Do We Mean by Learning Disabilities?**

Following psychological, medical, and statistical models, most LD researchers and practitioners use the individual student as its unit of analysis and so address “the personal qualities of those defined as having or being the problem” and, as a result, focus on “person-fixing rather than context-changing” (Linton, 1998, p. 6). LD has its roots in early post-World War II neurology; hence, there is an assumption of a neurological substrate (undocumented in individuals), which is thought to distinguish between those who are “truly LD” and those who

are misdiagnosed (Kavale & Forness, 1995). The field's greatest growth spurt paralleled the rise of psychometrics, because testing provided a way to identify operationally the purported discrepancy between potential and achievement. This disability category was legalized as a federally-fundable category of disability in the 1970s on the heels of, but two decades after, the Civil Rights Movement, largely through parent effort (Ferri & Connor, 2005). Sleeter (1986) argues this new label was welcomed, because it enabled schools to raise standards in response to our national embarrassment over Sputnik by providing a way to segregate white students who could no longer keep up with the accelerated instructional pace. Thus, students with LD did not have to share classrooms with students labeled as MR and EBD, groups composed mostly of racial and ethnic "minorities." LD's current formulation came after the "Great Society" turned its attention to the management, if not the eradication, of poverty, and LD simply preempted popular concerns for the "disadvantaged" as scholars began to view that term as both incorrect and indefensibly prejudicial (Carrier, 1987). Only recently has overrepresentation of students of color in LD become a national concern.

We understand the category of LD to exist through reification: After Admiral Rickover's (1957) press to improve science and mathematics education as a matter of national security, there were suddenly, as Sleeter noted, thousands of white, middle-class students who were no longer "making it" in general education classrooms. LD became a solution to the practical problem of how to accommodate simultaneously widely opposed racial integration and accelerated curriculum. Nevertheless, as we noted earlier, given the realities of schooling and the real problems that many students have in school, *LD exists*. It exists as a set of complicated and oppositional discursive realities (i.e., both the language and the practices that accompany it, are legitimated by, and in turn sustain language usage) that, in their positioning of students and their effects on their lives, have material consequences that are

all too real (see Reid & Valle, 2004, for an extended argument). As McDermott and Varenne (1998) note, many students and their families *have been acquired* by this label.

### Theorizing Impairment, Disability, and Difference

DS scholars typically use the term *impairment* to refer to natural human variations. Linton (1998, p.2), for example, defines impairment as "variations that exist in human behavior, appearance, functioning, sensory acuity, and cognitive processing." These "impairments" may be relevant to the field of LD, because there may well be subtle behavioral, sensory, and cognitive processing differences causally related to difficulties learning in school. We agree with Thomas' (1999) materialist argument that differences as experienced by individuals are more than the sum of parts of gender, class, race, sex, and sexuality. However, because we consider LD a discursive phenomenon formulated in the social nexus of power relations, rather than as a neutral term or a purely factual, material syndrome, we interpret impairment as a term that *already* assigns to difference a negative valence. In *The Birth of the Clinic*, Foucault (1994) explains to some extent how this happens when he traces the way clinicians came to *read the different body as diseased*, rather than as just in flux or *different* through time. *Impairment*, since its medicalization, has come to carry (albeit unnecessarily) an implied sense of limitation and residual *devaluation* that continues into contemporary culture. Indeed, the term *disability*, referring to the resultant oppression, should be understood as a reality that is immersed in "systems of representations, social and material practices, discourses, and ideological effects" (Thomas, 1999, p. 111).

Ableism, like racism, exists not only in material structures and experiences of prejudice, but also in conceptual and linguistic figurations and the systems of thought and practices that attend them. Disability is more than the palpable strains and inconveniences that individuals and

groups of individuals experience in their lives. Disability is, broadly speaking, an oppressive cultural enactment sustained and perpetuated through the myths, legends, jokes, anecdotes, narratives, and other discursive practices that circulate throughout Western society (see, for examples, Hall, 2000; Mitchell & Snyder, 2000; Stiker, 2002; Thomson, 1999). Hence, the importance of DS to our (re-)exploration of the field of LD and our proposal for a stepped-up alignment between the two fields.

### **An Alliance Based on a Critique of Educational Research?**

One way to re-imagine LD in terms of DS is to consider the possible ethical consequences of adopting similar research practices. As Gallagher (2001) states, the way we conduct research reflects our ethical choices. Unlike DS, most of the research in LD—and certainly that research which is considered acceptable by the mainstream (e.g., Macmillan, Gresham, & Forness, 1996; Scanlon, Boudah, & Elksnin, 2003; Swanson, 2000)—continues to be grounded in positivist science. Positivist science is “objective” research that takes the individual as its unit of analysis and is based on evidence derived from clearly stipulated and widely accepted experimental methods. These methods are often considered as the only neutral and fair ones in determining who is LD and who is not. As such, they also determine how students who acquire the label are to be “remediated” and where they will receive educational “interventions.” The goal of nearly all of this scientific discourse within LD is to probe the “misfit” between the student and the schools. And, because it focuses on what standardized testing says about what is wrong with a student, considered either individually or as a member of the group of students “with LD,” little attention is accorded contextual factors that more progressive DS-friendly LD researchers believe enact the disability. Despite the fact that most classroom accommodations are environmental—extended time, distraction-free settings, and preferential seating—research-

ers seldom conceptualize the “problem” of disability as a socially nested phenomenon, tending instead to ignore the sociological and historical factors that shape contemporary understandings of disability (Artiles, 2003).

### **Mainstream LD Researchers**

Unsurprisingly, mainstream LD researchers conceptualize variations in the pace of learning as *problems*, not as ordinary human diversity. Whatever evidence questions that orientation is largely ignored. For example, IQ tests used to measure the potential upon which the definitive proof of LD potential-achievement discrepancy diagnosis rests were, decades ago, exposed as biased measures of acculturation and achievement, rather than ability, as purported (Siegel, 1989; Siegel, 1995). Although achievement depends on the interplay of nature and nurture, the role of nurture in a labeled student’s life is certainly not examined either closely or extensively. Even worse, standardized achievement tests (through which presumed notions about disability are both often defined and confirmed) also reflect assimilation to what is sanctioned as knowledge legitimated by the white, middle-class (Darder, Baltodano, & Torres, 2003) and defined through the Eurocentric curriculum. Furthermore, Aaron (1997) in his review of the literature on dyslexia or “LD poor reading” and “non-LD” poor reading makes a strong case, based on the scientific literature itself, that there is no defensible evidence for the purported distinction between struggling readers with and without the IQ-achievement discrepancy.

Using a methodology that quantifies by “objectively” separating the knower from the known (Broun and Heshusius, 2004), researchers maintain the superficial appearance of fairness and, therefore, benign-ness of an approach that requires problems to be labeled, classified, and understood. However, these methods are not so benign as they seem. Positivist science as a *discursive practice* positions the research participant as an object to be examined—and the

perspective endures because positivist science always leads to more questions in an infinite regress (see Foucault, 1994). Indeed, the entire project of the scientific discourse in LD seems to be about identifying, examining, explaining, and remediating the students' problems, with little regard for the effects of such research on the people it examines. The onus thus falls on DS-aligned researchers to consider "the moral implications and social consequences of disability research" (Gallagher, 2001, p. 10).

### **Research Rooted in a DS Perspective**

Gallagher's seemingly straight-forward and ethical charge turns out to be a complex and thorny one, however. Moore, Beazely, and Maelzer (1998), for example, show how difficult disability-friendly research can be (i.e., research conducted to help labeled students frame issues they consider crucial for the betterment of their lives). Let us consider a relevant example from Moore, Beazely, and Maelzer's work in England. A parent, or professional-in-charge, considers an adult who carries an LD label (who in the U. S. might be labeled either "learning disabled" or "mildly mentally retarded") still childlike in the sense that he "requires" adult care and adult-imposed rules "for his own protection." This is a common assumption: That disabled adults need care and protection from the non-disabled (see Longmore, 2003). The researchers have a hard time figuring out who has the "best" interest of the disabled person at heart: Is it the parent, the professional, or the disabled man who wants to be thought of as a grown-up and who wants the same rights to self-determination as other adults? In such a situation, the researcher enters an ambiguous zone of decision-making where it is hard to know (if anyone can know) what might be best for the disabled person. Such scenarios can be additionally confusing when researchers have their own sense of who has primary rights. And, if that sense conflicts with the parent's or professionals' opinion, there may be rancor, difficulty securing extended participation of the disabled man in the study, or even withdrawal of fund-

ing. Other possible complications include having to make tough decisions about what to study (emancipatory studies that challenge the status quo are likely to be difficult to fund; see Moore et al., 1998, for an extended explanation), how much input from disabled persons is warranted (where do the boundaries exist between the demands of research and the needs of researchers and those of the researched?) and how to achieve a balance between being truly helpful or coolly distant, humane or opportunistic, probing or voyeuristic, and context-bound or context-free.

Unfortunately, in our opinion, it is rare to find among LD researchers the kind and degree of sensitivity that Moore et al. (1998) bring to their work. Because of the rigorous procedural regulations of positivist work, recognition of such thorny dilemmas is virtually absent. This is one of the possible benefits of the alliance between DS and LD that we seek. If professionals in LD were to take more seriously the difficulties and consequences Moore et al. address, they could open up spaces for a new crop of broadening insights that may reveal the, as yet largely unexplored, positive aspects of labeled persons' life experiences and shift the focus from the person labeled to the enactment of disability within and across various contexts in which their lives take place.

### **The Counter-Discourse in LD**

There is, however, a separate, more progressive and more hopeful counter discourse that exists within the LD research community. This alternative discourse emerged from the critiques of the medical-scientific, deficit-oriented, mainstream perspective. Brantlinger (1997), Carrier (1986), Dudley-Marling and Dippo (1995), Heshusius (1989), Poplin (1988), Poplin and Pamela (1983), and Sleeter (1986, 1995) have all questioned traditional school practices and their positivist underpinnings. This discourse, however, has not yet moved to center stage, even though it has become increasingly powerful and visible (Anderson, 1995; Wong, 2004).

Some more current work continuing in this vein includes recent studies by Collins (2003), Dudley-Marling (2004), and Reid and Valle (2004b). These scholars, all using actual classroom transcripts, demonstrate how, through the discursive reality of LD, differences come into contact with cultural assumptions—obviously a concern for DS scholars too. They analyze interplays between teachers' ideas and expectations about difference and ways they exercise power to confirm those assumptions that play out in actual classroom practice. The result is confirmation of the maxim that “you get what you see” and a sense of clarity about how, on the micro-level, disability is actually enacted in classrooms. But, these studies tend to address disability as a free-standing factor, one separate from other personal identity factors.

Losen and Orfield (2002), however, have documented clearly how minorities are seriously overrepresented in the high-incidence disability categories of special education, disabilities that are psychometrically defined such as LD, mental retardation, and emotional and behavior disorders. In both DS and LD, we are all concerned with the long-standing debate on how to live by democratic principles and also address more conscientiously than before the need for more situated understandings of human experience—understandings that recognize the intersectionalities of race, class, gender, sexual preference, first language, and so forth, with disability. Artiles (2003) argues for such an approach when he calls for the analysis of both the discourse of “inclusion as rationale” and of “inclusion as implementation.” The former refers to students' moment-to-moment experiences in school, examining the varied contexts that support (or not) students' active self-expression. In contrast, with respect to the latter, Artiles urges deconstruction of the structural limitations associated with stigma that minority groups face. Disability constitutes one of those stigmas and so must be considered simultaneously in the mix. Because they disrupt the positivists' tendencies to frame students in essentialized and “timeless”

(i.e., ahistorical) frameworks and to ignore a particular people's (e.g., the Latino/a's) unique history with poverty and oppression, these two lines of ethnographic LD research could be very promising.

To elaborate, Artiles (2003) makes a powerful argument for how some racial/ethnic groups have prevailed against “incredible” odds to relocate and survive. He laments that our scholarship in high-incidence disabilities tends not to tell students' stories with such histories in mind. He argues for a third space of conceptualization, in which we view culture as a constant dynamic between the micro- and macro-levels of a person's existence—a project useful to DS as well. Indeed, as former teacher-practitioners in the inner city, we often wondered whether students in our classes receiving services for LD were labeled because of their unfamiliarity with Standard American English and culture, rather than for problems noted in the LD definition, and the data on overrepresentation justify our skepticism. Gersten (1994) writes that teachers are increasingly, “uncertain about how to determine whether bilingual students are experiencing problems due to learning disabilities or due to their limited comprehension of the English language” (p. 311). He further reports an accelerating pattern of misidentification, misplacement, misuse of tests (testing in English rather than the students' native languages), and concomitant poor academic performance even within special education. Obviously, there are social justice issues we need to explore more deeply: How disability, race-ethnicity, and poverty become conflated is an obvious and an important one. But, there are also more subtle difficulties to be identified and investigated as well: For example, the way the language of testing and the testing of language reinforce our assumptions about LD (See Reid & Valle, 2005, for an extended discussion).

However, respecting individual experiences with disability while focusing on the broad, social barriers that define disability as a minor-

ity culture, even as a matter of policy, is hardly enough. As researchers, we need also to understand inclusiveness as an *internal reality* for a person who considers him or herself (or who is considered by others) to be different. As Peters (2002) suggests, for true fulfillment, a person cannot accept standard definitions of beauty, culture, and history against which to measure the self. Nor should researchers, who are equally bombarded by these Western standards, take such constructs for granted. Postmodern epistemologies, with their emphasis on pluralism, assist us in becoming sensitive to discourses that unfairly keep each of us—disabled, non-disabled, student, or researcher—from appreciating our own and others' differences as unique and acceptable.

Disability-friendly researchers then have an ethical responsibility not only to study the positive aspects of LD—students' agency, resistance, and accomplishments—but also to support students in becoming adept at detecting how cultures arbitrarily position them as “less than.” Perhaps, as Artiles (2003) suggests, they can do this by comparing the interactions between micro- and macro-levels of students' existences. In this way, both the researched and the researchers can achieve real autonomy. As academics, we share a basic ethical responsibility to ensure that our inquiry promotes understandings about what reality is and how we come to know it that both allow and encourage students, their families, ourselves, and others to imagine a different, more just world order (Greene, 2003). It is not enough to gauge the integrity and quality of our individual research studies. We must evaluate their collective consequences as well.

### **An Alliance Based on a Critique of Educational Practice?**

Over the last several decades, DS scholars (Barton, 1998; Biklen, 1985, 1988; Biklen & Zollers, 1986; Erevelles, 2000; Gallagher, 2004;

Ross-Gordon, 2002; Ware, 2001; Wilson, 2000) have made it eminently clear that current models of special education are incompatible, and in fact run contrary to the tenets of DS, primarily because of their deficit orientation, their reliance on binaries (e.g., normal/abnormal), their focus on individual characteristics, and their positioning of disabled students as subjects, rather than as sovereign agents in their own lives. These incompatibilities resist resolution for many reasons. First, our continuing emphasis on what is wrong with students obscures the problematic factors in the *school environment*, i.e. (a) the lock-step, age-related, Eurocentric curriculum, (b) Eurocentric standards for classroom and academic behaviors, (c) the assumption that the only acceptable mode of discourse is Standard American English, (d) the separation and lack of alignment between general and special education, (e) the legislation that instantiates Taylor's (1911) positivist model of instruction based on principles of accountability through assessments of outcomes and objectives, and so forth. The list is a long one and we have given only a sampling of problems here.

The point is that educators and the public in general have come to take for granted that schools must be, should be, as they are. We accept the dictum that schools are expensive and so must operate as efficiently as possible and that their efficiency derives from educating students in homogeneous groups. We believe that medicalized and psychometric diagnoses are viable and fair ways to sort children into such groups. In addition, the federal imposition of standardized, high-stakes testing and funding requirements for labels works not only to convince us schools must operate in prescribed and traditional ways, but holds us accountable for doing so. These assumptions and practices lead to one conclusion that if the schools are okay, then the source of the difficulties in a notoriously ineffective educational system must lie in student diversity. An alliance with DS could help us turn the spotlight away from the students and onto



the cultural and educational systems that disable them.

For example, one very powerful insight from DS is how popular conceptions of normalcy pervade our cultural and institutional practices (Davis, 1997). The arts, literature, historical records (or lack thereof), and general media coverage dictate popular beliefs that shape and sustain educational practices as well as attitudes toward disability. These beliefs converge with disciplinary knowledge—medical, psychological, and educational—to define who is normal and what is normal practice. However, these perceptions of the normal are a function of political and historical pressures, decisions, and accidents (Foucault, 1981; Skrtic, 1995). Perceptions of normalcy are shifting constructions; not immutable, natural categories.

From DS, we might borrow a postmodern, pluralistic lens through which to (re-)examine this *situated interplay of language, bodies, and institutions* that, in a practical sense, defines LD—as it does every other disability. Scholarship in DS implies we need to challenge unitary, universalized explanations of LD not only within classrooms, but within schools and clinics, between districts and states, and across nations as well. Ghai's (2002) work in India, for example, recognizes a set of unique histories and conditions that inform people's thoughts and actions differently across the Indian subcontinent. As a result, she argues, conceptions of disability cannot be directly transplanted to fit Western models of reality. To study LD (or any other disability) in India requires attention to fragmentation and local situations.

This same fragmentation and changeability pervades every culture and every classroom. Only when teachers become sensitive to and accepting of individuality as valuable and unique can they begin to set aside their categorical expectations for "LD students" and understand the un-reality of a positivist educational system. There simply is no "normal" pace for our ap-

proach to learning. Through such awareness, they can replace the mental image of "a unified and individualistic subject... with the *indeterminate subject* constituted and reconstituted in multiple ways" (Ghai, 2002, p. 95, emphasis added). Indeterminacy promotes the ability to shift perspectives and to tolerate ambiguity, so that teachers can make the moment-to-moment, situated judgments that disrupts the social process that enacts disability.

Given our inability to make any judgments about students from their disability labels, we are also likely to profit from DS's model of studying (auto)biographical counter narratives. We have very few narratives (Levine & Osbourne, 1989; Reid & Button, 1995; Rodis, Garrod, & Boscardin, 2001; Trumbull, 1991) written by people publicly labeled with LD, so we know little about their analyses and representations of the world. When educators insist we see differences for what they "really" are (i.e., impairments), they ignore their own power to represent. It matters that we become more aware of how we frame students' bodies, because how people are positioned through language and materiality (in short, discourses) says a lot about how much power they have (Foucault, 1981).

However, being conscious that discursive systems give birth and sustenance to words used to reposition difference as impairment, such as we do when we label someone LD, does not dilute the significance of the lived experience of the people so labeled. If work such as Shuttleworth's (2002) chapter on the intimate confessions of men with cerebral palsy in search of love and sex can stand as a testament to the power of representation in lived experience, we do not see how to justify dichotomizing between reality and representation. For example, Shuttleworth states that the men he describes in his study have "sequences of intentions and feelings... [that are] only sensible within a culture's system of meanings and structuring of social relations" (p. 115). Like Shuttleworth, we do not see how we can divorce the "systems of meanings" from the

reality of students' school lives. How students identified as being in the LD category negotiate such framing—what they accept, reject, resist—is exactly the type of awareness that should inform our judgments. And that kind of information does not come from the observations of outsiders.

Furthermore, despite our aversion to labels, so long as they are required and used, we need scholarship that reads LD as a distinct category of difference, unlike physical and sensory impairments, one made visible only through performance in a particular context. We must explore the consequences for such bodies considered abnormal (i.e., *having* or *being* LD) and also for the emotions evoked—the micro-level, personal response to inclusiveness we addressed previously—by such students' lived experiences.

In addition, an educational system premised on the growth and affirmation of each student would certainly be more ethically appropriate than this current system of competition that highlights conformity and regards individual differences as problems-to-be-remediated. Disability-friendly teaching, like disability-friendly research, would explicitly teach students strategies to build a critical awareness of the world and of their own places in it (Freire, 1970)—to help them acquire tools needed to assert their competence and to self-advocate. One means might be learning to deconstruct (to think critically about) text—talk, print, visual images and so forth. As Cherryholmes (1993) writes, through deconstruction students learn to “see the power of the text as shifting and requiring continual justification and re-justification, authorization and reauthorization” (p. 19). Instead of trying to determine the author's meaning as if it were a fixed “fact,” students learn to *attribute* meaning to texts and re-signify them.

Furthermore, teachers must negotiate ways to provide all students access to text, whether they speak or not, read on grade-level or not. To

assume students cannot interpret and respond to text because they cannot read it independently is to deny them their right to a “free and appropriate education” (IDEA FAPE; 20 U.S.C. secs. 1400(c) and 1412(1)). Only by providing students with opportunities to interact and learn in ways not determined by their differences (in the current climate labeled as impairments and disabilities) can teachers help promote self-awareness. Moreover, only by changing their approach can LD teachers design instruction to fit the student rather than the other way around and this reversal is necessary if they are to encourage students to read their own bodies and question the discourses that disempower them.

As the continued rejection of the DS-aligned LD discourse by mainstream LD scholars makes clear, the LD community cannot accomplish such important change alone or even with the support of other educators. There must be structural changes in schools that depend on public attitudes and commitments. Only through supportive coalitions of students, families, community members, academics, activists, and agency providers will we be able to shift the focus from rigorous science to the moral consequences of our research and educational practices. In solidarity with and building on the work that is being done in DS and by disability activists—work that supports the progressive discourse that already exists within LD--the possibility for change has the potential to increase dramatically.

### **What Does an Alliance Offer DS?**

Because one of the primary and ultimate goals of DS includes promoting understanding and acceptance, not for some disabled people, but for everyone who experiences the marginalization of disabling oppression, the most compelling reason DS could benefit from an alliance with LD is the sheer number of people involved. There are large numbers of people who are not likely to be widely represented in the academic

or even activist communities any time soon, as a result of their disabling experiences. The numbers are already staggering and are poised to increase as educators continue to place just less than half of 12% (the legal funding limit) of the increasing school-aged population in the LD category (see Aaron, 1997). The inclusion of LD in the DS discussion would work to diminish the *disability hierarchy* (Fleischer & Zames, 2001; Mitchell & Snyder, 2000), favoring physical and, more controversially, sensory differences over the less visible, more contextualized and performance-based ones, such as cognitive and emotional differences. Ironically, these latter disability categories depend more essentially on social constructions than do those that have physical and sensory substrates (Ferri & Connor, 2005; Losen & Orfield, 2002; Reid & Valle, 2004). These disabilities are not only constrained by social attitudes and barriers, they are defined by them psychiatrically and psychometrically.

An LD label can lead to severe marginalization, particularly for the less affluent and for students of color. In public schools, students with LD are often placed in segregated classes in dead-end low tracks where expectations are lowered, curricula are watered down, and the pace of instruction is slowed (see Aaron, 1997; Blackorby & Wagner, 1996; Gersten, 1994; Tomlinson et al., 1997). Instruction often consists of uninteresting and unmotivating repetitive drill and practice. Few students with LD are ever returned to general-education classrooms, because the nature of the remedial education they receive tends to ensure the students it serves continue to need remediation (Tomlinson, 1999). Their life courses are altered and their life chances, particularly with respect to higher education opportunities and employment, frequently diminished (Hehir, 2002; Powell, 2003). Instead of fostering students' unique abilities, protecting and expanding their rights, and providing opportunities for real growth and active social participation, schools tend to prepare these students to accept their "natural," lower rank by

continually reminding them they do not "fit," and positioning them at the margins. Unfortunately, many grow to accept the low-status view the schools have of them as their station in life (Hehir, 2002).

It is because of the definitional loophole created by murkiness about the nature and boundaries of the high incidence disability categories (i.e., LD, mild mental retardation and emotional and behavioral disorders), that special education has come to serve as this *official* tool of institutionalized racism. The fuzziness of the categories opens a space to support "fabrications" that justify the placement of disproportionate numbers of African Americans and other cultural and linguistic minorities in segregated classrooms (Linton, 1998; Losen & Orfield, 2002). As DS historian, Baynton (2004) suggests, the subjugation of minority peoples, particularly women and black slaves, was in part constructed by associating them with various aspects of disability—weakness, stupidity, etc. Furthermore, educated white males have led most of the disability movements in Europe and America (Fleischer & Zames, 2001; Peters, 2002; Thomas, 1999). We juxtapose that observation with the obvious fact that the same has been true throughout the history of American education: Although education is clearly a feminized profession, its leaders have always been dominant-culture men (Grumet, 1981; Tyack, 1974). One outcome has been that women and minority students have become significantly undervalued, just as have students with disabilities. The story of contemporary special education clearly suggests race-ethnicity-gender-disability confluences are continuing in mutually supportive ways. Still, academics from both the LD and DS fields have been slow to study the problem of minority overrepresentation in segregated programs for labeled students, the literal well spring from which "disabilities" emerge. Given the commonalities that Baynton (2004) and Smith (2004) describe between the function of race and disability in DS and in sanctioned educational practices that affect the large numbers

of students labeled LD, joining forces seems like a promising venture.

It may help to work against Thomson's (1999) assertion that there are tacit complicities among institutions that speak and intend one thing, but do another. Since many DS scholars are interested in interpretive studies typically aligned with the sociological, literary, and arts traditions, they may not warm to the positivist (medically- and psychologically-based) research and practices that predominately characterize the field of LD. Nevertheless, education represents a cultural institution central to the problem of stigma (Goffman, 1963) by providing and perpetuating the breeding ground for such entities as LD, which respond to the needs of the cultural institutions rather than those of the students (Carrier, 1986; Sleeter, 1995; Thomas & Loxley, 2001). DS stands to benefit from an alliance with LD (and other categories of disability) because of a mutual interest in subverting current, deeply entrenched, yet clearly destructive and unwarranted practices that are likely to continue into perpetuity—unless we actively and forcefully oppose them. The sooner we blend these disciplines, the more likely it will become that we prohibit the indoctrination of yet another generation of disabled and non-disabled students into a medicalized and stigmatizing model of disability.

Although we have focused in this argument on common concerns, permeating borders between DS and LD would certainly unveil tensions. Re-examination in light of these tensions, may, as we have suggested, help LD scholars achieve a new awareness of the biases in the traditions of positivist inquiry and deficit-driven approaches to education that keep us from risking new moves towards formulating how difficulties in reading or other language-based academic problems can be better accommodated, understood, and destigmatized. DS, on the other hand, would have to take on a much broader scope and become more comprehensive and contextually human than ever before,

reaching, for example, as far as language-literacy communities that label six-year-olds as impaired because they do not match school norms (Gee, 1999). With our combined expertise in critical social analysis, we might turn our cultural gaze toward dismantling the educational-medical-social systems that “oppress and obfuscate, exclude and excise” the LD community (Smith, 2004, p.13).

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(Endnotes)

<sup>1</sup> We have taken up and followed the distinction put forward by the translators of *Outsiders*, who add the following clarification to Becker's definition of "social norms": "Here, as almost always in *Outsiders*, Becker uses the term 'rule'. We have translated this term by "norme" when it means all of these varied forms, or when it means more specifically, informal rule that influence the behaviour and judgements of those who smoke marijuana or of jazz musicians. In other context, particularly the examples borrowed from the administrative and legal domains, we also use the terms "rule", "regulation"

and “law” (Becker, 1985, p. 26).

<sup>2</sup> For example, Rod Michalko (a blind author cited in Smith & Ervelles, 2004) argues that the “person-first” language (e.g., a person with a disability in contrast to the preferred *disabled person*, the latter of which reflects societal oppression) so pervasive in the educational literature demonstrates “normate” (Thomson, 1999) society’s demand that, for disabled people to be accepted, they must demonstrate that their disability is an unessential feature of their being.

<sup>3</sup> Several studies show a pattern of overrepresentation of minority groups in the category of LD, and special education generally. For instance, Zhang and Katsiyannis (2002) present recent demographic information showing minority overrepresentation in all three categories (LD, MR, and EBD). The greatest gap exists between the number of white students and both blacks and Native Alaskan students placed in special education settings, respectively, as judged by the proportion of whites to blacks and native Alaskans attending schools. In addition, data show Black and Latino/a students have been over-represented in LD for several decades (Brosnan, 1983; Tucker, 1980), although not to the same extent as in the MR and EBD categories (Losen & Orfield, 2002). In Connecticut, Lipsky and Gartner (1997a), mention that researchers found that 36% of non-white males and 34% of non-white females labeled as LD were put in segregated special education classes, whereas white males and females combined constituted only 15% of that group. Lipsky and Gartner (1997b), furthermore, state there is no reason to believe this is unique to the state of Connecticut.

<sup>4</sup> We thank Sue Baglieri for this idea.

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