

The Winston Churchill Memorial Trust of Australia



REPORT BY

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To evaluate organisations promoting the benefits of accessible environments, universal design and assistive technology with emphasis on implementation, funding initiatives and political issues – USA, UK, Denmark.

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Signed: Jane Bringolf

Date: 21 January 2005

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INTRODUCTION

My quest was to find out about organisations focused on the topic of inclusive design and technologies that benefit everyone, particularly people with disabilities and older people. My findings were both professionally liberating, and personally life changing.

The Fellowship Program brought me new friends, an international network of kindred spirits, and an increased passion for the cause in Australia. I met some amazing and generous people - many more than I hoped for. They shared their experiences, ideas, issues, and their personal time to help me in my quest. I have returned filled with enthusiasm, and a strong sense of responsibility to use my Fellowship experience to best advantage for the Australian community. In brief my main discoveries were:

Many of the disability support organisations in the United States are staffed by people with a disability; that universities play a role in service provision as well as research and education; and that the disability movement identifies with the rights movement, but that legislation is still to be properly enacted.

Whilst legislation in the United Kingdom is in place to eliminate or reduce disability discrimination, enactment is still elusive, because the building code is not fully designed to support the intent of the disability discrimination legislation; and that organisations are increasingly forced into the charity model of funding as government funds diminish.

Commitment to people with a disability in Denmark is based on a culture of solidarity and equity. The prevailing attitude of inclusivity diminishes the need for anti-discrimination legislation. Funds for appropriate housing and assistive equipment are readily available, and home modifications and equipment are as close as the nearest local council offices.

An unexpected finding is related to the levels of hidden and denied disabling conditions. I found that even people prominent in the field of advocacy for people with disabilities are hiding their own disability. What does this mean for a) the rest of society, b) the measurement of disability in the community, and c) for the design of our world, new technologies and public policy programs? These remain largely unanswered, but important questions.

My thanks to the Churchill Trust for providing a remarkable opportunity to learn with and from people overseas, to my employer, Independent Living Centre NSW, for granting me the time to undertake the Fellowship, to my referees, and to the many people who gave generously of both knowledge and resources to support me in my quest overseas and at home. I am indebted to you all.

EXECUTIVE SUMMARY

The Fellowship was to investigate organisations in the US, UK and Denmark relating to accessible environments, universal design, and assistive technology. The knowledge gained will contribute to the establishment of an Australian centre for accessible design and assistive technology.

The US, UK and Denmark each have organisations that are considered centres of excellence in their field. The Center for Universal Design, the IDEA Center, Rehabilitation International, Centre for Accessible Environments, Disabled Living Foundation, and the Association for the Advancement of Assistive Technology Europe are all regarded as leaders nationally and internationally.

Whilst cultural, economic and political influences vary across nationalities, everyone I met demonstrated absolute passion for the cause. In terms of establishing the organisations, it was people of vision and commitment who decided that a centre was needed and then set about making it happen. “True believers” – people of vision and commitment continue the work. As in Australia, passion for the cause keeps these organisations moving forward.

Anti-discrimination legislation in the US and UK has much in common with Australia. Such legislation does not exist in Denmark as the approach is for inclusiveness and “solidarity”. Whilst civil rights underpin US legislation, equality of opportunity underpins the Danish approach. In the US, UK and Australia, the needs of people with disabilities is the province of health and human service departments. In Denmark it is the responsibility of all instrumentalities to ensure that barriers to participation and independent living are overcome. It is a problem-solving approach rather than a rules-based approach.

Simple phrases of fact and experience, particularly by people with a disability, are the way to get the message across. “There are two kinds of people in the world, those with a disability, and those not yet with a disability” is one such message. It spells out that disability comes to us all eventually. It is not exclusive or assigned to a special group. Another is, “Universal design is good design for everyone, not just people with a disability”. Inclusiveness can be designed and built into everyday life with a little extra understanding of the varying abilities of people, providing amenity for everyone.

Australia has no national organisation that is considered a centre of excellence: a place where anyone can go to find out about the things that can create inclusiveness, nor does it have a national centre for international relations on accessibility, inclusivity and assistive technology. The time to establish such a centre has arrived and the Independent Living Centre NSW has begun work on the project.

The learning and information from the Fellowship will be disseminated by public presentations, journal and magazine articles, websites, and through the proposed centre.

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FELLOWSHIP PROGRAM

United States of America

South Carolina Assistive Technology Project (SCATP)
Evelyn Evans and the AT team
Richard R Ferrante

Centre for Universal Design (CUD)
Laurie Ringaert, Executive Director

Library fro the Blind and Physically Handicapped
Gary Ray, Director of Volunteer Services

North Carolina Assistive Technology Program
Annette Lauber, Funding Specialist
Lynne Deese, AT Consultant

Alliance of Disability Advocates and Centre for Independent Living (ADA-CIL)
Rene Cummins, Director

Partnerships in Assistive Technology (PAT)
Tony Hiatt, Executive Director

Joy Weeber
Disability Rights Activist

RESNA (Rehab Engineering & Assistive Technology Society of North America)
Larry Pencak, Executive Director

The World Bank
Judith Heumann, Advisor, Disability and Development
Terry O'Brien, Alternative Executive Director

IDEA Center (Centre for Inclusive Design and Environmental Access)
Prof Abir Mullick, Design Engineer
Jordana Maisel, Urban Planner
David Feathers, Research Assistant, anthropometrics
Dr Scott Danford, Behavioural Psychologist
Danise Levine, Architect
Alex Bitterman, Information Architect

RI (formerly Rehabilitation International)
Tomas Largerwall, Secretary General

United Nations
Vittoria Beria, Associate Social Affairs Officer

United Kingdom

Disabled Living Foundation (DLF)
Nicole Penn-Symonds, Executive Director

Centre for Accessible Environments (CAE)
Paul Highman, Principal Information Officer

Disabled Living Centres Council (DLCC)
Alan Taylor, Acting Director
Annette French, Regional Development Officer
Julia Blundell, Training Coordinator

Manchester Disabled Living
Jackie Whitworth, Style Centre Manager
Barbara Ackley, Style Centre Clothing Advisor

Netherlands

iRv, Institute for Rehabilitation Research
Harry Knops, President of AAATE (Association for the Advancement of Assistive Technology Europe)
George van Lieshout, Program Manager Integrated Accessibility
Dr Ir Mathijs Soede, Program Manager Assistive Technology

Denmark

The Danish Centre for Technical Aids for Rehabilitation and Education
Anne Christensen, Consultant Occupational Therapist
Lone Kajer Junker, AAATE Secretariat Coordinator

BACKGROUND

In my role as Executive Director of the Independent Living Centre NSW, I am increasingly involved in issues of accessible environments, universal design and assistive technology. Universal design is about designing products and environments that can be used by everyone without the need for adaptation. Assistive technology (AT) aims to compensate for individual functional loss and includes everything from tap turners to hi-tech speech devices. AT is not intended to overcome poor environmental and design features. For example, less people would need tap turners if tap handles were designed for easy use as well as style.

The need for a national centre to promote an inclusive world and progress specific aspects of accessible environments, universal design and assistive technology has long been acknowledged by people with a disability and those who work in disability services. Much is already being done, but it is fragmented. A national centre can do several things: act as an information clearing house, prevent duplication of effort and identify gaps; act as a resource centre for the general public, construction industry, engineers, designers, health professionals and community groups; and participate in the development of public policy.

The social and economic benefits of creating environments, products and services that are easy to use for everyone cannot be overstated. More people can get jobs, go to school, and participate in community life generally. The demand for social and health services would be reduced if people can live more independently and safely in their own homes. The economic benefits of this are obvious.

The US and the UK have nationally (and internationally) recognised centres of excellence. They contribute to the national and international dialogue on issues of access, universality and technology. Some contribute to the body of research and others to the establishment of services and resources in developing countries as well as their own. They are all resource centres with information for everyone.

HAVE WHEELS CAN TRAVEL

Come with me on a journey to discover a little of the work being done for people with a disability in US, UK, Netherlands and Denmark. With a view to setting up a centre for accessible environments and assistive technology, we can find out what to do and perhaps, what not to do. I have computer briefcase on wheels which will illuminate areas of wheeled inaccessibility as I travel.

We shall travel from Sydney Australia to Columbia SC, Raleigh NC, Washington DC, Buffalo, New York City, London, Manchester, Maastricht and Copenhagen. We shall hear the stories first hand of people with disabilities, and we shall meet people who are working towards designing and constructing a world where everyone can participate in everyday activities with equity, dignity and amenity.

United States of America

Columbia South Carolina

Wide streets, open spaces, and a rural feel welcome me to Columbia, a university town. Fast food outlets abound and most seem to cater reasonably well for people with wheels. However, I notice that some of the facilities do not connect well, with a step here and there between the door and the toilet, for example. I am here to see the first organisation on my list, the South Carolina Assistive Technology Project (SCATP).

I meet Evelyn Evans and the team in their display room that has lots of electronic assistive devices and some other products that are aimed mostly at the school age child. I discover that they are the nearest equivalent to Independent Living Centres (ILC) in Australia. Their display is small and does not reflect the breadth of their service.

I have my first lesson in disability issues in America. Whilst anti discrimination legislation has its roots in Civil Rights, SCATP people believe there is room to do more because it is the right thing to do, not just because the legislation says so. I get the impression that the Americans with Disabilities Act, founded on civil rights principles, is hailed as the solution to the key issues.

Richard Ferrante, the Director of the Center for Disability Services where SCATP resides, talks of the technical revolution and web accessibility and how they are helping other state agencies with their accessibility with no extra funding. Without funding, small and incremental ways are the method to get things done. They have 900 people on their Listserv and provide practical assistance to others in this way. They do many more things, but most importantly, they seem to fill the gaps left between service types and this seems to be done more from a vision and a commitment rather than a specific program, and certainly there is no funding for this type of activity. Their website is very good with lots of information about the centre, assistive technology (AT) and ways to get help.

Being part of a university, the Dept of Medicine in this instance, seems to offer security and there is opportunity to mix theory with practice. SCATP has direct access to medical students to help educate them on disability issues, and easy access to research can benefit the SCATP practise.

Two hours pass very quickly and we discover that we are kindred spirits because of our passion for the work. I leave feeling I have made friends for life. My first learning point is that a relatively small, well managed organisation, placed within the appropriate setting, can achieve much. Although there is insufficient money to do all that is required, the staff make things happen through their enthusiasm and problem solving approach. Obviously, this enthusiasm can only be fuelled long term by a supportive environment for their ideas and methods.

Raleigh North Carolina

Next stop is Raleigh and the Center for Universal Design (CUD) based in the College of Design, NC State University. I arrive at my hotel to find a welcome message from Laurie Ringaert from the Center. She is picking me up at 7pm to take me to a play, which is part of the Accessible Arts program. I experience the audio description service that is designed to improve the enjoyment of people who are blind and vision impaired. I hear the describer over a radio device and an earpiece. It is like having someone whispering in your ear describing actions and non-verbal language on stage. The describer doesn't talk all the time, only when necessary. I gradually adjust to having this in my ear. It must make a great deal of difference to a person who is blind or visually impaired.

Next day, I get to know Laurie over breakfast. She is Canadian and was part of the disability movement in Winnipeg. She is a qualified occupational therapist, but her experiences with disability became more personal when she contracted fibromyalgia. She is mostly recovered from this now, but was in a wheelchair for a while. It is easy to see where her passion comes from. Her personal experience and technical training make a powerful combination.

Laurie is fairly new at CUD and it would appear that the previous executive director has left Laurie a difficult situation. We go back to the office and the place is makeshift. They have been moved out of their regular accommodation, and it is a dilapidated cellar of an old building. There are no windows that I can see. The sign for CUD on the front door is handwritten on a piece of paper attached with a thumbtack. In my opinion, they do such good work, they do not deserve to be in such substandard premises. Staff have left because the funding situation is so uncertain.

Apparently CUD and IDEA at Buffalo were to compete for funds – the federal funder body would not agree to fund both of them, even if they agreed to splitting available funds. It transpired that neither centre was funded. CUD is threatened with closure in December 2004, but IDEA is in a better financial position and their university seems to offer more support. The CUD university seems uninterested in helping their cause. Laurie is frantically trying to get funds from somewhere to keep going. We discuss the value of such an organisation

being within a university set up. It is hard to imagine that such a well known national centre offering such a wide range of resources for the community should be at risk of shutting down. (Postscript: the university closed the Center at the end of December 2004, as no funding was forthcoming.)

My lesson for the day: the value of a program to the community is never enough to ensure continued funding – you must stay relevant. Even if the main message or vision does not change, new ways of presenting the issues must be found otherwise the organisation will look stale and stagnate. Also ensure you are auspiced by and networked with enthusiastic people and organisations.

Off to a presentation lunch for access awards put on by the local Mayor's Committee for People with Disabilities. There is a large screen to one side of the speakers where the speech is instantly typed up and shown on the screen. This captioning is very good for hearing impaired, but I found myself somewhat distracted with my fascination for the techniques of translating speakers into the written word and the automatic phrases that the electronic system uses to assist the typist.

Laurie takes me to see Rene Cummins of the local Center for Independent Living (CIL). These centres are focused on advocacy and community education, and information and referral. Rene received an award at lunch for her work. Rene is closely involved with a number of activities including Accessible Arts projects. CILs in US must have at least 50% of both staff and the governing body as people with a disability. This is part of the funding charter. Rene says there should be more CILs in North Carolina to meet the population needs. There are only three and this one is less than a year old.

We go back to the university to look at a newly produced CUD video on bathrooms, toilets and water fountains. This is basically the equivalent of our Australian Standard 1428 brought to life. It is very well done and if the measurements weren't in inches, the ILC could probably use it. Most importantly, it shows builders how people in wheelchairs transfer to the toilet and how they use the grab rails and why toilet roll holders need to be placed correctly.

The Library for the Blind is not easy to find and is an old building in a factory strip along a divided highway. It is part of the State Library of North Carolina. Laurie takes me to see Gary Ray who turned out to be the outgoing MC at the access awards presentation yesterday. Gary gives me a business card with Braille overlay and large print on the reverse side. He puts my business card under a magnifier for his computer screen reader so that he can read it. I feel my card is inadequate – even Laurie has large print on the reverse side of her business card. I make a mental note for my next print run.

Gary is Director of Volunteers. He uses every opportunity to promote the organisation by being involved with as many other activities as possible, hence his high profile at the access awards ceremony. He sees forming strong networks with other organisations as the best way to position the organisation. The Library is now a major county resource centre. Gary says that it is

important to be everywhere on the issues. I ask if this is an organisational vision, but, no, it is just his vision. Another lesson here: no matter what else has to be done, keep up the networks, join in, be seen as a player, have an opinion, do not work in isolation.

Gary talks also of the civil rights movement. He, along with others, clearly believes in the power of the legislation (the Rehabilitation Act and the Americans with Disabilities Act) underpinned by the concept of civil rights.

I form the opinion that he is a great asset to the organisation, but because he is not the executive director, he may be acting outside his brief from time to time. No matter, in the short time I spend with him, I think he is a great advocate for the cause. He is able to attract volunteers (he has 120) and is full of great illustrative stories. His personality and communication style become imprinted in my memory. Another lesson point: persuasive and passionate people will make a difference regardless of rules and funding.

The Library for the Blind is a reference for people with all kinds of disabilities. People who are blind or who have a vision impairment often have other types of disability and this is one of the reasons why the full name of the organisation is "Library for the Blind and Physically Handicapped". They consider themselves major players in the assistive technology (AT) field. Gary showed us around the facility with its huge warehouse of taped materials, the workshop for repairing tape machines, the mailing house, the recording rooms where volunteers make the sound recordings, the Braille machinery, the computer section where software such as Jaws can be demonstrated and trialled. It was hard to imagine that half a million books are mailed out each year until I saw the warehouse.

Next stop, Tony Hiatt at Partnerships in Assistive Technology (PAT) which works with the North Carolina Assistive Technology Project, a government-run organisation. PAT does the things a state agency cannot do, which includes receiving payment for services, doing mail-outs, and being tax exempt. Basically, these non-profits are set up to get around the government bureaucracy. PAT runs two main programs: it has a database of second hand equipment for sale, and an adaptive fishing program in collaboration with the Wildlife Commission. It also runs the state Technology Expo, which is attended by 750 people each year. A lesson here: non-profits can deliver some things more effectively and flexibly than state-run organisations.

A quick visit to Lynne Deese at the North Carolina AT Program which is federally and state funded as are all AT programs in the United States. The room looked like a smaller version of SCATP. It is mostly communication technology, although Lynne says they provide information on other products. However, they refer people directly to equipment suppliers. Funding for equipment is an issue and Annette Lauber explains her role in seeking funding for clients to buy assistive equipment.

After lunch I meet Joy Weeber. Laurie explains that Joy was married to Ron Mace, the founder of the CUD and the founder of the barrier-free environments movement. Ron, an architect, was a wheelchair user all his life, and died four

years ago. Joy greets me as if we are long lost friends: her warmth radiates. I like her instantly. She tells me Ron's story, and also hers. Growing up with polio, many months in full body casts, an iron lung and struggling to be "normal" until one day in her 30s she realises and accepts that she has a disability and her life changes for the better. Joy inspires me to talk of my own experiences with disability and the quest for "normality", and how the issues of "difference" continue for a lifetime.

Joy talks of her thesis on denial of disability by individuals and families. She explains her personal experiences, and her project, and how the disability is not discussed in families. Joy and I share common experience of sibling relationships and discuss how we are socialised and normalised. This is not the same concept as overcoming discrimination. This is a quest, by families and individuals, as far as possible to try and overcome difference. But I ponder to what avail? If this normalising paradigm continues, how will that help the cause for a more inclusive society? We need the society paradigm to change to accept greater degrees of difference, not the quest by those who are "different" to fit the prevailing social attitudes.

Joy shows me a video interview of Ron Mace filmed just two days before he died. It is a great interview and I feel as if he was in the room talking to me. I understand so much more of the history and the passion behind the cause for universal design. Joy is truly an inspiration. She has clearly thought through so many of the issues and turned me into a person who now relates more closely to the disability community, not just a service provider do-gooder. She makes me comfortable with the feeling for the first time in my life. My lesson from this? I am not sure, as it is more about my personal growth, which is always of benefit somehow. No doubt this afternoon will make more sense as the rest of the trip unfolds. I have much to reflect upon.

Arlington and Washington

The Americans with Disabilities Act doesn't seem to have reached as far as the Virginian Suites, my apartment building for the next few days. There are six steps up to the reception counter and no other way to reach it. My room has a bathroom door that is about 55cm wide, apparently an old standard. The way to the nearby shops is over the busy main highway via a footbridge. It has a flight of steps at each end. Too bad if you rely on wheels. I discover that Arlington is on steep to undulating terrain and not very wheelie friendly anyway. It must mean taxi transport everywhere, or everything delivered if you don't have your own car.

I have time to visit Washington DC to do some sightseeing. At the Metro station, I am met with rows of ticket machines in the dark and cavernous station foyer. Tickets are issued only by a machine, which requires dexterity to feed coins into slots and an ability to understand the instructions and the transport map. However, I discover a friendly attendant who is prepared to help me get a ticket. An elevator to the platform is helpful. I wait on a darkened platform – a much bigger tunnel shape than the London Underground. The walls are made of huge profiled concrete blocks and with the dull lighting and grey and black

colour scheme it reminds me more of a fairground ghost house. I'd hate to be more visually impaired than I already am! I wonder about overall safety levels for everyone.

The Smithsonian Institute is made up of several imposing buildings on either side of a long, wide grassed mall. Every type of museum and gallery is housed here. Separate entrances abound for people reliant on wheels or who cannot manage steps. At the entrance to each building there is the international symbol for accessibility and an arrow showing where the ramp entrance can be located. As many of the buildings have imposing front entrances complete with long flights of steps and stone columns, the accessible entrance is somewhere to the back or the side of the building where a ramp can be situated.

The National Museum of the American Indian shows elements of universal design throughout the building. It is a brand new building. High-tech and innovative methods of the information displays do not compromise the ancient cultures. Of course there are lots of things about the exhibits that are not designed for accessibility, such as storyboards with writing overlaid on watermark type pictures, and the generally low light levels. The layout is a maze style which is not helpful to people with a poor sense of direction.

I am committed to inspecting all the accessible toilets on my way around the Smithsonian centres. They all vary so much! It would seem that in Australia, well in Sydney at least, accessible public toilets (or easy access toilets, some are called) all have the same standard features. I noticed a separate accessible toilet labelled suitable for a "companion" and it had Braille signage as well. I have not seen that before.

Inside other buildings I notice that the accessible toilets are often one cubicle located in the general bank of toilets. A hand basin is not included in the cubicle as it is in Australia, so people are left to the vagaries of the standard basin layout. I also notice that one outward opening door at the end of a row is obstructed by a wall heater, so the open doorway width is reduced. Silly little door latches mean that trying to close the outward opening door behind you is almost impossible, especially if it is placed too high on the door. Lesson point: you can build things to a standard, but that doesn't always make them accessible. In many instances the Devil is in the detail. In New South Wales local councils often insist on access consultants viewing plans and buildings to ensure the detail is attended to.

Next day I put in a call to Judy Heumann at the World Bank and leave a message. The World Bank website has some great information I see several references to Judy Heumann who looks like a real trailblazer. This is a whole new world. Here in America, the disability movement is very strong on the notion of "nothing about us without us", that is, people with a disability must be involved in all decisions relating to them. I realise I have been lifted to another plane in thought and ideas and I will no longer think just in Australian terms. I am already changed and I have another three weeks to go. Tomorrow is the day to meet Larry Pencak of RESNA.

RESNA is a professional association formed by rehabilitation engineers some 25 years ago that has strong links with sister organisations in Australia (ARATA) and in Europe (AAATE). The offices on the 15th floor look just like most organisations that have to maximize outputs with minimum inputs. Larry welcomes me warmly and we go to the small meeting room. He gets down to business right away and starts with the history of the organisation and that of assistive technology, rehabilitation engineers and physiotherapists. He is another person to say that the disability community is a group you can join at any time, in fact, everyone will join it at some time. They have three credentialing programs: one for AT practitioners, one for AT suppliers, and one for rehab engineer technologists.

Members were asking for the credentialing program and RESNA took the risk of investing money in the education program - around \$150,000 in 1992. The risk was that it did not bring in revenue for several years, but it is now providing an income of \$300,000 a year. It also draws more people to the organisation world-wide. It was a good long term decision because the need for credentials became a necessity when clients could only get reimbursement on their insurance or Medicaid if they were serviced by a "credentialed" practitioner.

Lesson point: setting up an education/credentialing program is expensive, but where there is a credentialing vacuum, better to be first with a program and become so well known that no-one tries to compete. The need for credentials in emerging professions will always be apparent. Being first is important as only one credentialing body is required.

Larry says that regardless of medical advances and improvements in rehabilitation technology, the AT industry will continue because there is still much to develop. Science fiction is becoming a regular thing for everyone and will remain in demand. For example voice recognition in the car to control the radio, the phone, the GPS and the CD player. This is good technology for everyone (universal design), not just those who cannot use their hands. However, there are some technologies that are only effective if the built environment is designed appropriately and services are available. For example, being able to call up a taxi hands free is of no use if you cannot get into the taxi, or the place you want to go is inaccessible. I ponder whether Sci-Fi is the way to promote the efficacy of aids and devices to older people. I also begin to wonder if more of the population would use powered wheelchairs if the built environment catered better for them. Powered wheelchairs are a good transportation device, and wheelchair manufacturers and suppliers are perhaps missing out on expanding their market.

The economic argument is not lost on Larry. He says we live in a capitalist society and the economic argument will always win over the social justice argument. This means explaining social justice issues in economic terms. To this end, the work of rehabilitation engineers is beginning to migrate from departments of health and human services to commerce departments who can see a multi-billion dollar industry booming before them. This means that the government sees AT and rehabilitation as a profit centre rather than a cost centre. Add in universal design ideas to the mix and a new set of products for a

whole range of consumers begins to emerge. Big lesson point here in changing the paradigm from health to commerce and therefore cost to profit.

Larry talks of the growth of AT in SE Asia, particularly Hong Kong and Japan. He has refused invitations to go to Australia because it is too far away. Perhaps there is an opportunity to set up a credentialing program with the help of ARATA in Australia. Just as my time is up, Larry's assistant brings in a message from Judy at the World Bank asking me to call her. I am impressed that she has tracked me down at Larry's office.

I call Judy and we agree to meet at 3.30pm. The World Bank takes up about four blocks with its offices. As I approach the main building I notice great concrete traffic barriers all along the footpath and all the parking metres are hooded. Obviously security measures for the World Bank. The extra concrete in the streetscape does nothing to enhance the ambience of the area.

The World Bank offices are just like any other – cluttered with desks cheek by jowl. Judy is just like her picture on the website and I feel as if I know her already. The World Bank is now committed to inclusion, participation and access. She says access is the easiest of the three to implement, but it is where the least has been done in the world. Judy is a dynamo, recognises that a much her job is to educate World Bank people, apart from advising projects. She is keen to link me with as many people as possible and immediately contacts Terry O'Brien, an Australian who is working in the executive suites. He has something to do with World Bank projects that utilise Australian and New Zealand money. He has time to see me this afternoon.

Terry tells me more about how it all works and I let him know that when it comes to using Australian funds to construct a school or community facility in a developing country, we have resources to help make them accessible for everyone. Although wheelchairs and baby strollers are unheard of in some of these places now, the early buildings still need to incorporate universal design principles. My connection with the World Bank has brought the realisation of how important it is to be part of an international network. I feel globalised.

Buffalo New York

The University at Buffalo houses the IDEA Center and RERC within the Faculty of Architecture and Planning. IDEA (Inclusive Design and Environmental Access) sponsors the RERC (Rehabilitation Engineering & Research Center) which is more specifically about universal design. I'm welcomed into white walled rooms that are very well heated. They have a program of activities set out for me for the two days. My first session is with Jordana Maisel whose project is about visitability of domestic housing, that is, designing houses that can be visited and utilised by people with disabilities. She is also working on public policy in the housing sector. I discover that there is a big distinction between accessibility and universal design in America and Jordana spells it out. The former is about building to the building code for people with disabilities, and the latter is about designing for everyone. I say they are the same thing in Australia, or that at least, we think they are.

Scott Danford, an applied behavioural psychologist is looking at how people actually use buildings and public spaces. His project is essentially about validating claims that universally designed environments are easier to use, and work just as well for everyone. The latest study, in a set of three, was observing people in Las Vegas using hidden video cameras. They are soon to publish a DVD video of the results. I am very lucky to be shown advanced screenings that clearly explain the problems of existing street and facility designs. The film also shows how the diagonal cut across the corner of a kerb at intersections is dangerous for wheelchair users and parents with strollers. A cut at on each side of the kerb facing the opposite kerb, as generally used in Australia, would be much safer.

I meet Abir Mullick, industrial designer and urban planner, who has developed prototypes of flexible bathrooms and shows me a whole range of design features that I have not seen before. He tells me that Disney is interested in some of this for their hotel rooms as they are all about the “magic” concept and futuristic design. I see a lot of other prototypes in their lab and some of the things the students have done. Abir is one of the developers of the seminal “7 Principles of Universal Design”.

David Feathers is a mechanical engineer who is focusing on anthropometrics (study of body size, shape and movements, and reach ranges) and is constructing an anthropometric database. He is supervising a masters occupational therapy student who is looking at how, why and when wheelchair users swap between manual and power chairs. David’s research is connected also with wheelchair and scooter circulation spaces and how they compare with their Standards.

Next day I am back to the campus for an appointment at the Center for Assistive Technology. I find the building OK, but there are no signs, directions, or indicators. I have a phone number as well as the campus map. A recorded message provides lots of options. After two false starts a real person speaks to me and says to come to level three and she’ll find someone to sort it out. Lesson point here: Signage is important, as is a phone system that has a default for person to person contact.

I get out of the lift to find the reception desk and the receptionist ignores me. It quickly dawns on me that she is blind. I say good morning and she recognises my voice/accent. Katie Beaver greets me and takes me to their technology room. We just get started and Doug from the Independent Living Centre interrupts us. I learned previously that Doug is blind and that he would be coming collect me. I speak to introduce myself as no-one else has introduced me yet and I want him to know I am there. Doug tells Katie he will bring me back later.

Doug negotiates his way out of the building using his cane. His secretarial assistant is waiting to drive us the short distance to the ILC. The building is on the main street and is a battered looking shopfront. Doug takes me on a tour. The building reminds me of Dr Who’s Tardis - it seems to be so much bigger on the inside than the outside, and I don’t see any windows anywhere. I meet

briefly with virtually all the staff, one at a time. Each gives me a brief run-down on what they do. The Native American Independent Living Centre is staffed by people from the different nations and is run in parallel to the main ILC. There is also a mental health program for assisting people to transition to work and the community. Service users staff this program. They believe it provides greater credibility with clients.

I am starting to get really clear now that these centres for independent living are rather like the disability specific advocacy organisations, such as the MS Society and ParaQuad in Australia. Centres for independent living are like all these organisations rolled into one in terms of “transitioning” people to live independently. This means taking their lives as a whole and getting them linked to transport, jobs, education, housing, etc. However, this particular ILC has gone one step further. It is also running a project to help all ILCs to function at optimum levels. It is doing this through training projects and collating data on about 300 ILCs in the US, and using this data for disseminating useful information in a clearing house fashion.

Doug talks of many things and I just listen trying to take it all in. I sense he has a unique management style (possibly influenced by his army training). He tells me that when a project receives an income of \$250,000 a year, he turns it into a department and the project manager becomes a director. Directors form the senior management team under the executive director. When directors get more money for their project, they get a pay rise. Doug says it encourages growth. Judging by the size of the centre, I think his reasoning is sound.

Doug is yet another political campaigner, and because centres for independent living are about advocacy and self help (remembering that at least 50% of workers and 50% of the board must have a disability), there is a bit of confusion over what I know about the rights movement and advocacy. I have to explain that my ILC is more like an AT centre, not an advocacy organisation. Here, having a disability is a qualification in its own right when it comes to working in the field. I don't think it is seen this way in Australia.

I am very impressed with this centre and feel that Doug has much in common with Gary Ray at the Library for the Blind in North Carolina. They just forge ahead with what they believe in, creating and constructing their organisations as they go. Passion is clearly a qualification for this kind of work. I am beginning to see why disability is regarded as a qualification – discrimination drives the passion.

Back at the AT Centre Katie Beaver shows me all the different things they do and how they have developed a program/system for producing tactile maps that aid the learning systems in schools. Also they are working with Smartboards – the electronic whiteboards that are used in computer-linked Net Meetings - to have them introduced into more schools. A visually impaired child can see what the teacher is writing on the board on a laptop on their desk. This laptop can be configured to suit their visual ability and of course, they only have to press the “save” button and they have the notes instantly! Why wouldn't every student want this? The way of the future? Another instance of universal design – the

people who make Smartboards didn't envisage this kind of use for their technology. This AT centre is rather like the others I have seen. It is interesting that they are attached to universities. I am not sure if all AT centres are auspiced by universities.

Katie offers the opportunity to try out speech recognition software for myself. It is a really great technology and opens up the world to so many people who find reading and writing difficult for all sorts of reasons.

Across campus and back to IDEA to meet Danise Levine an architect who primarily works on private dwellings either designing both new and modified dwellings. She has a PowerPoint presentation set up and takes me through it. I silently start to notice the absence of occupational therapists in this endeavour and within IDEA. Whilst Danise is clearly doing some great work, I think to myself that an occupational therapist could make a useful contribution with a focus on the practical aspects of living with a disability.

Quickly on to meet Alex Bitterman, a communication designer and information architect with an interest in the development of identity systems (icons) and the graphic display of information. He is also editor of "Diversity in Design". He has just started a three year research program on graphic symbols to represent accessible and universal design, and an identity for Universal Design proper. Alex has lots of other interesting items to share about how people interpret symbols and data, but my time is up and it is time to prepare for the next stage of my journey.

IDEA's strength is not just in its research capability, but also in its diversity of disciplines all working for the one goal. I think there is much to learn from this example.

New York City

I arrive in New York with a better understanding of the legislation and the disability movement in the USA. As I go about my business I start to conclude that the legislation is not very helpful when it gets to street level. So many examples of poor design and thoughtless placement of things. A row of concrete barriers has been placed at a bus stop and they impinge on the circulation space of a wheelchair user and attendant so that entry into the bus is only possible with a lot of manoeuvring and my help. I fear that the much lauded legislation has not provided the world the American disability movement believes it has.

I meet with Tomas Largerwall of RI (formerly Rehabilitation International). He is very gracious and spends three hours with me. He gives me contact details of three people at the United Nations and suggests I call right away to see if one of them can meet with me tomorrow. I learn a lot about RI – how they plan to change the name (Rights and Inclusion) to better reflect what they do, how they are working in developing countries, the links they have with Judy Heumann at the World Bank, and a very interesting history of the organisation. It was begun in 1922 as a local organisation for crippled children. A fine example of how a

local organisation can become globalised, again with people of passion, belief, and vision; a small amount of funding to get started; and capitalising on political events, such as rehabilitating war-injured personnel. They have changed their name five times in 70 years to meet with the current trends and work.

RI is the organisation that developed the most well known symbol in the world, the blue and white sign for accessibility that we all see on car parking spaces and accessible toilets. They recognise the problems with the sign, the major one being the contradictions in meaning. In a car parking space it signals exclusive use for people with a disability. Anywhere else, such as toilets, it means inclusive use by everyone. Maybe the graphics work of Alex Bitterman at IDEA can help solve the problem in the future.

Tomas provided a very important insight as he took me through the hall of fame pictures in the office. Many of the key people in RI in the past have had a disability, but have hidden it wherever possible. I can understand why this is so. Apart from their voluntary contribution to RI, they all held other roles, some high ranking professionals and academics. They were not prepared to take the risk of their professional peers discovering their disability for a well-placed fear that they would then be considered incompetent (or half a person) in some way. Not much has changed – generally people with disabilities are still considered as “incomplete” people, and therefore incapable. However, it is paradoxical that a person working passionately for an organisation trying to improve the lives of people with a disability, is unable to expose their own disability.

I reflect on my conversations with Joy Weeber and her work on denial of disability. What is disability anyway? How is it measured? How many people are hiding or denying a disability? The estimation in the developed world of around twenty percent of the population is largely based on individuals identifying with the term, or being medically labelled for social security and other benefits. What about older people who do not claim to have a disability, just arthritis, or diabetes, or inability to walk far? What is the real figure – thirty, forty, fifty percent? Perhaps this is not such a marginalised group after all, maybe functional loss or inability is much more prevalent in our society. If say, fifty percent of the population was designated as having a functional loss (eyesight, hearing, walking ability, breathing difficulties, heart conditions, arthritic conditions, etc), what would that mean for social policy, the built environment, and industrial design concepts?

I also reflect on Judy Heumann’s comment, “There are two kinds of people in the world, those who have a disability, and those who do not yet have a disability.” Given that disability or functional loss comes to us all with time, it can only be our denial and hiding of disability that allows the world to be designed as if functional loss was confined to a small section of society. Question is, how do we get everyone to “come out of the closet”? With an ageing population, clearly more work is needed on this notion.

Vittoria Beria is off on another United Nations mission to Africa tonight, but has kindly fitted in a short meeting with me. We start our conversation in earnest right away in the lift to her office in the UN building. Vittoria does what many

others have done and goes through her contacts to see which ones I already have and those I don't. Networking is clearly an important and valued thing, and now I feel well and truly ensconced into this international network. It is understood that my contact details will also be given out to interested parties in the future. Lesson note: Networking is important, being part of an international conversation makes for credibility as an organisation, but being known personally as a member of the "campaign" is equally important.

Vittoria gives me an overview of what the UN is trying to do in relation to disability. There are only four people in this unit. The Convention on the Rights of People with a Disability is taking most of their time right now. Their aim is to get disability issues as part of other issues, not a separate endeavour. We discuss universal design as being a key to the whole thing. The UN's view is that the disability world is closed and this is little help to people with a disability – the UN is interested in "mainstreaming" the issues. My thoughts on denial of disability return. If the stigma can be removed, then denial will cease to be such an issue, and the true level of disability can be measured.

Once the UN Convention is established, member countries will sign up to the rights of people with a disability, and will be under pressure to make sure they uphold those rights. Putting them into practice will be another thing and this is where the role and promotion of inclusive/universal design will play a major part.

United Kingdom

London

I walk into the Disabled Living Foundation (DLF) building in South London. It is a large open area with all types of equipment, aids, devices, and furniture on display. It is an old building and the display looks as if it has been there a long time. It looks dull and lifeless, similar to the display the ILC had in its old building. However, everything to aid daily living is there for people to try out and examine.

ILCs in Australia were modelled on the DLF when they were set up some twenty years ago. Several ILCs have moved to newer premises in this time and their displays look fresher now. However, the philosophical basis and operations of the DLF and ILCs has remained the same over time. The DLF was the first and only such centre in the UK for many years, but now they are part of a network of Disabled Living Centres across the country and mostly serve their local area around Hammersmith and Westminster. Their equipment database remains their mainstay, but this may not last for much longer. Their electronic database is sold to all other disabled living centres and is a major source of income, £300,000 a year. The advent of the Internet providing access to much more information generally, and European equipment databases expanding and globalising, have posed a serious challenge to their "ownership" of information and therefore a large portion of their income. Also, with other databases freely available, they are under pressure to do likewise. The future looks difficult as funding for this type of service is competing with so many

others. They are forced more deeply into the charity model of fundraising just to survive.

I am shown a newly developed interactive self assessment program on the computer which they will put onto their website very soon. By answering some simple questions about what you can and can't do around the home and daily life, you end up with a listing of products that are likely to help you, including the supplier details. A kind of do-it-yourself occupational therapy assessment! They hope to have it available in pharmacies, shopping malls and other places where people gather to make it easy to access. The touch screen method and large font make it easy to use.

I use the London Underground to get to the Centre for Accessible Environments (CAE). Flights of steps greet me at every turn and I have to carry my briefcase on wheels several times. I see no lifts, so the Underground is still largely inaccessible for people with wheels. In the street the cobbles look pretty, but are no good for wheels. In some places they are used to good effect by edging walkways providing directional cues, and a form of sensory information for blind people. But I suspect it is just a designer's idea of keeping the heritage feel of the new work.

The CAE is in a very London looking building, nothing special, but not dilapidated looking like the DLF. Paul Highman greets me at the door and ushers me into a meeting room. He gives me an overview of the British approach to environmental access. Whilst there is some legislation and British Standards, the focus of the Act is on the outcome not the process, that is, how to provide the service, not design the building. For example, the Shakespeare Theatre in Stratford has interactive kiosks so that people can "see" the first floor of the theatre from the ground floor. Access auditing will become part of the work of local authorities and will be part of risk assessment and occupational health and safety and compliance with legislation. As the legislation is complaints based, case law is going to be the only way to get change in the future. It seems the "hardship" clause is applied to smaller businesses more readily than in Australia. Generally, architects see issues of accessibility as an imposition on their creativity rather than a challenge.

The CAE's training programs on access auditing and consulting appear to focus more on meeting the requirements of the legislation than the needs of the population. They also hold the national register of access consultants who have successfully completed their training. There is no similar qualification or registration in Australia, and I did not discover anything similar in the US where people with a disability are being encouraged to be access advisors using a checklist methodology. Lesson linked with RESNA: Get in first with the training and credentialing and establish credibility early.

The CAE also produces some great publications that are highly regarded. Being a charity, they also provide an information service free of charge. The CAE has many resources and is clearly helpful to the construction industry and local authorities. With a focus on meeting legislation rather than the needs of people

with a disability, I wonder in what way they contribute to the disability cause through social policy and the development of standards.

Manchester

The Disabled Living Centres Council (DLCC) and the Manchester Disabled Living Centre (DLC) are in the one building located in an industrial area. So many charities have a familiar feel about them. Old buildings in low cost locations, where it looks as if every last ounce has been squeezed from it.

Alan Taylor whizzes around the corner in his power chair to greet me in the reception. He works for the Manchester DLC, but is currently performing a caretaker manager role for the DLCC, so he is able to talk about both organisations interchangeably. They have many programs of interest as well as training courses for professionals on aspects of equipment prescription, a great website newsletter and many other resources. They also rely heavily on public sponsorship for their programs and much time is devoted to this and maintaining a high profile.

The product display centre has a familiar feel – I could be in an Australian ILC. One or two things are quite different, especially the purpose built shower cubicles, which Australia doesn't really go in for, and they have two display kitchens – one for wheelchair users, and one for other disabilities.

Alan has the added advantage of being able to provide great anecdotes to emphasise situations for people with a disability. One of these didn't need words, and it was the buttons in the lift still being set too high for a wheelchair user. However, they are about to sell the building and have something purpose built. During the day he commented that he did not consider himself as having a disability until he developed diabetes. I thought immediately of Joy Weeber and her thesis on the denial of disability.

I visit the continence program, PromoCon, which is quite a large and busy section of the organisation, and then onto the Style Centre. This is definitely something new to me. People of short stature, wheelchair users and people with asymmetrical body shapes all have difficulty getting clothes to fit and many just give up and buy shapeless stretch fabric garments to keep themselves covered and warm.

The Style Centre challenges established concepts of dull and shapeless clothes. People with a disability are not exempt from wanting to look and feel good. Mostly they dress as they do because it is too hard to get clothes to fit or to put on. I think style, fashion, and clothing are a neglected area and they will become more important as more people with a disability are included in regular schools, colleges, and workplaces. Younger people don't want old-style floral, petal-back clothes because they are easier for carers to dress them – they want the latest styles, the same as their friends. To be able to go to the school formal wearing a great outfit is a major emotional need for a young person, as is, dressing appropriately for a job interview. There is no government funding for this – charity money has to pay for this program. Maybe that is why this seems to be the only one.

The Style Centre developed from a Russian program aimed at overcoming limb deficiency. Chernobyl, frostbite, wars and workplace accidents are the cause of much limb deficiency. The Style Centre runs a five day style and fashion program where a class of five, mostly young people, design, cut and sew their own garment. They also get advice on colours and hairstyles that suit them. Many of the students have an intellectual disability, and the program does wonders for their self esteem.

The Style Centre also designs clothes for people who continually undress, self-harm, and for one who eats their clothes. Really large people find underwear impossible to buy, so they go without it. Now they can have the comfort of underwear the same as anyone else. I thank Alan for spending so much of his precious day with me, and I say goodbye to yet another kindred spirit.

Netherlands

Maastricht

I arrive at iRv in the Institute for Rehabilitation Research, which is a complex of several buildings resembling a university campus near Maastricht. Manager Strategy, Harry Knops greets me warmly and takes me two storeys to his office. The brightness and lightness of windows is refreshing. I also meet George van Lieshout and Mathijs Soede. Harry expresses his views and I can see why he is the President of AAATE (Association for the Advancement of Assistive Technology Europe). He believes strongly in the social definition of disability, not the medical definition. I feel he has been influenced by his international connections, because he explains that Europeans want to cling to the medical definitions of disability. The social definition of disability is a key factor in bringing about change. Medical definitions only describe and denote what a person is unable to do, not what they can achieve.

George takes me for a tour around the centre, which once again is like an ILC. However it has a lot more space to display items and kitchen designs (and it seems to me, money and time). It also looks bright and fresh, unlike the Disabled Living Foundation in London. I am introduced to some leading edge technology for safety door locks for people living alone, and a program using a video phone.

History and cobbled streets are everywhere in the centre of Maastricht. Some of these are newly laid, no doubt for heritage reasons. As wheeled access is virtually impossible, (even bicycles have issues with cobbles) I assume that wheelchair users and parents with strollers rarely come to this part of town. Judging by the queues at the bus stops, the bus system is well used, and there are buses coming and going from every direction. However, I saw no signs of accessibility on the buses.

Denmark

Copenhagen

More cobbles greet me in Copenhagen city centre. I arrive at the front door of the hotel only to be met by a small revolving door. I need to make three trips, each with one bag as there is barely enough room for me in the door section, let alone baggage. Three steps up are immediately inside the revolving door. Upon asking how a person in a wheelchair gets access, the response is a thoughtful face and an explanation that they have two other doors into the premises. However, steps are still involved with both.

Unlike the Netherlands, there are no English signs or directions, and the Danish language bears no resemblance to any language I've encountered before. I have my first real experience of not having any idea at all what the messages are telling me. This is especially problematic where there is full automation of Metro stations. Automation is a good thing, but if the instructions are not in a language you understand it is a bit hopeless. I cannot understand the instructions on the ticket screen nor the number pad for my credit card. Apart from no train drivers, there are no platform staff. I have to ask for help from a fellow passenger. Lesson here is not to assume that everyone is literate, or able to interpret information correctly. Pictograms might have helped a bit.

The Metro is very modern but the railway system still utilises very old rolling stock. Nevertheless, new trains have three substantial steps up to the carriage door. Perhaps it is something to do with high speed trains travelling through stations. They have automated the doors but you have to push a button. I wonder if there is some special mechanism for wheelchair users and people with strollers, but there is nothing obvious. The taxi drops me at "Gate 38" in an industrial complex on the edge of the city centre. This is the address for the Danish Centre for Technical Aids and the secretariat for AAATE.

I talk with Anne Christensen and Lone Kajer Junker about AAATE. Events and circumstances brought this situation about and had much to do with the director of the centre at the time having a "can-do" attitude. He strongly believed the organisation needed to be started up and took the lead of a small committed group. Once again, the lesson is: it is the person to make the first move that sets the foundation for the future.

AAATE is built on the collective enthusiasm of committed volunteers working in the technology field in Europe and elsewhere. This is the same for ARATA in Australia. The membership has grown through word of mouth. They publish a technical journal in English covering a wide range of AT topics including home modifications.

The Danish Centre basically houses offices and a testing laboratory. The actual equipment provision for AT is done at a local level at each of the 276 municipalities that run the equipment loan scheme. A social worker coordinates the scheme at the local level and there is no cost to the user. The Centre is the knowledge resource for the municipalities and they sell their 25,000-item

database to them. The local centres use the database for equipment information and for stock control of their loan items. This link means the Danish Centre is the knowledge centre for the equipment provision system, and this will help ensure their future.

The product suppliers keep this huge database updated. They access their products on the Internet version of database. Suppliers sell directly to the municipalities. If they want their product available, it is in their interests to enter their product data. There is a pro forma for entering information. One full time person checks the suppliers' input to ensure quality control.

I meet Klaus, the IT person who shows me the project for bringing together the databases of Norway, Sweden and Denmark. They have used the ISO 999 classification system for technical aids for their databases. Now there is another project underway for linking existing equipment databases in Europe (EASTIN). The Disabled Living Foundation in London will eventually be part of this major project.

In the testing lab adjustable beds are being tested and they have just started work on mattresses for pressure relief. They also test overhead track hoists. Sweden, Norway and Denmark each test different types of products and share the research information. ILCs in Australia are doing their best to share resources in a similar way. We share in common with European organisations the issues of different funding bases, political issues and imperatives, and cultural styles. The European initiative is a mammoth undertaking for this reason alone. Internet-based technology makes it all possible, but agreeing on issues of difference is where the hard work lays. The lesson being reinforced here is the power of shared information and resources. Together so much more can be achieved for the cause.

The Danes do not have disability discrimination legislation. Concepts of solidarity and equalisation of opportunity underpin the cultural basis for achieving and maintaining equity for citizens. At the time the Americans with Disabilities legislation was being developed Denmark decided not to go down this track. Danes, including those with a disability, feared that introducing legislation to separate one group of citizens from the rest of society would prevent rather than promote equal opportunities. Finding solutions to ensure equal opportunity for all citizens is the responsibility of all authorities and government departments. It is not left to the health or social services departments as it is in other Western countries. The taxation system funds the assistance required to bring people the best opportunities regardless of ability in any form.

In the US, the concept of solidarity is between people with a disability. I think there is much to commend the Danish argument because in spite of the legislation, people are still marginalised. Australia has much in common with the US in spite of claims for egalitarianism. It has always been a conundrum for me that in Australia (and the US and UK) that the fight for disability rights has been for inclusion. Even the name of the legislation (Disability Discrimination Act) is focused on what people cannot do (disability) rather than what can be done

(equal opportunity). In societies where minimum taxes and maximum profit are higher values than equity and opportunity, there is no other option but to form action groups.

Apart from the new Metro system, I found the city centre of Copenhagen virtually inaccessible. Cobblestones, steps up to shops and steps down to semi-basement shops all add to the ambience and quaintness of this well established city with its Teutonic architecture. However, I saw two people in wheelchairs waiting outside shops at the foot of steps. Anne Christensen explained that the built environment and home modifications had been given a lot of attention recently. However, it seems the legislation for access is for new premises only. Centuries-old buildings still house major services and facilities, but they are not going to change based on current legislation. There is also a general opinion that too much attention has been given to the environment at the expense of AT and that the pendulum needs to swing back the other way. I found this approach quite interesting as AAATE is promoting technology and access as part of the same continuum.

SUMMARY AND CONCLUSIONS

Nothing about us without us

Changes in society are always hard fought by the people who can sustain the passion for the cause. Anger about the status quo is often a driver of passion, particularly where personal experience of injustice is involved. For others, it is compassion that drives their actions to overcome injustice. Judging by the people I met, the passion is most deeply held by those who claim to have a disability. However, there is much compassion in those who “do not yet have a disability” but realise one day they will.

A strong disability movement in the US has driven the change thus far. Many of the services based around independent living, assistive technology and accessible environments are run by and for people with a disability. The phrase “nothing about us without us”, coined some years ago, is manifest in having people with disabilities involved at all levels on any issue or service that is about disability. For example, The World Bank was pressured into appointing a person with a disability to lead a newly created department on disability and development. Disability has become a credential as well as an attribute.

Nevertheless, for all this positioning, it appears the driving force is economics rather than rights. For example, the emphasis given to transitioning people with a disability into paid employment is more about reducing social security payments than about applying rights. The comments by the executive director of RESNA about transitioning assistive technology (AT) development and provision from human services departments to those of commerce also signals a conceptual shift of taking disability from a cost centre to a profit centre.

Rights do not of themselves make for change. It is people who make change. Rights legislation can offer comfort to those whom it protects, but laws do not necessarily effect a change in attitudes or behaviour by those who are required to uphold those rights. Legislation that is enforced, such as workplace safety, can bring about behavioural change. However, disability discrimination legislation in the US, the UK and Australia does not have the same enforcement provisions as workplace safety legislation. Individuals are required to take legal action to have their legal rights upheld. It is the precedents set in these legal actions that have changed behaviours in New South Wales. Fear of prosecution, not notions of equity, has caused planning authorities and some local councils to demand that buildings meet the disability legislation as well as the building regulations.

This is where the role of access consultants is crucial. Access consultants ensure that the intent of the disability discrimination legislation is met, as well as the building regulations. I was informed that access consulting is not developing as a profession in the US in the same way as it is in UK and Australia. From my observations, many buildings probably comply with the building regulations for access in the US and the UK, but few are fully accessible. In the US, people with disabilities are being encouraged to assist building owners provide accessibility. However, in this case, the credential of “disability” is insufficient to provide functional environments for people with disabilities. In this instance, “nothing about us without us” fails to help provide suitable outcomes. The approach taken by Australia, that is to enforce the intent of the legislation, is providing many more successful outcomes in the built environment. The role of access consultants in ensuring the intent of the legislations is met is crucial. As access consulting is a new profession there are no credentialed courses available yet. A credentialed course similar to that offered by the Centre for Accessible Environments in the UK would provide standardisation of knowledge and outcomes.

Integration, inclusion and equity

The Danish system is based on entirely different principles to that of rights. It is based on solidarity and equal opportunity for all. When the US passed legislation proclaiming the rights of people with disabilities, the Danes, including those with a disability, decided that such legislation would undermine their principle of solidarity. They feared legislation specifically for people with a disability would cause a separation of this group from the rest of society, preventing equal opportunity rather than promoting it. With a tax funded system that caters for all needs, there is no “fight for rights” required. Energies are directed towards creating possibilities and solutions for all citizens. Whilst people with disabilities are not protected by anti-discrimination legislation, the parliamentary statement of principle about the equalisation of opportunities has provided sufficient protection. Much of the development of their approach was influenced by the United Nations “Standard Rules on the Equalization of Opportunities for Persons with Disabilities”.

The responsibility for including people with disabilities rests with every area of government and is not confined to health or community service departments.

This whole of government approach reflects the inclusive nature of both policy and service provision. Apart from providing advice and support, disability organisations engage in dialogue with authorities and government on policy development. Clearly the prevailing cultural norm of inclusivity has served the Danish citizens well. Good social policy becomes good economic policy in the longer term. The ability to participate in society (get a job, go to school) can only be brought about by compensating for functional loss with AT, and by designing built environments that suit everyone.

Measuring disability

A recurring theme in the US was that disability will come to us all in time – some sooner than others. Judy Heumann of the The World Bank spells it out, “There are two kinds of people in the world, those with a disability and those who do not yet have a disability”. Discovering that prominent people in the field of disability rights and services had hidden their disability was a revelation. I am not sure why I should be surprised when they are only protecting themselves from possible diminution in the eyes of others. After all, they know of the discriminatory attitudes that prevail – being judged by what you cannot do rather than what you can. Or, as Joy Weeber has discovered, some people deny their disability in their quest for “normality”, to be the same, not to be different.

Older people do not relate to the notion of disability and euphemise their functional loss as not being able to walk far, to hear well, to turn on taps, to bend over, etc. How do you measure disability in the community if individuals do not consider themselves as having one? The Australian Bureau of Statistics reports that nineteen percent of the population has a disability. That is one in five people. Does that really include everyone with a functional loss? If wheelchair users can say they don't have a disability because their wheels replace their legs, in the same way that spectacles overcome vision loss, what level of disability are we really talking about? I would venture to suggest that the real figure is more likely to be one in two people having a functional loss of some type, be it physical, intellectual, or psychological.

Marginalisation encourages secrecy and denial. If disability was not kept secret or denied, the true levels in society would be revealed. At an individual level, judging whether or not you have a disability is of little consequence to others. However, collectively it could have a significant impact on the creative directions of industrial designers and architects, and on the ways in which service providers think about delivering services. It would also have an impact on social policy and engender a whole of government approach.

Accessible or Universal?

Universal design or inclusive design is more than access to buildings, facilities, and services. “Accessibility” is about designing things specifically for people with disabilities. “Universal design” is about designing for everyone, everywhere, in their everyday lives. Universality, therefore, encompasses accessibility.

Detractors argue that it is impossible to be everything to everyone, and can even result in useless designs. This is an extreme view in the eyes of the universal design supporters. No design solution should make a situation worse. Some new designs may exclude some users, but include more than before. Progress is one step at a time. Other solutions lay in the provision of multiple facilities such as low height and regular height automatic teller machines side by side. Difficulties in design are challenges for universality, not an argument against it. The research programs at the IDEA Center at Buffalo are showing how all types of designs can be made universal. The project dedicated to proving that universal designs are better for everyone, not just people with a disability is showing positive results. This augers well for the movement and it will set new challenges to all types of designers.

A national centre is needed

Disability is as assured in our lives as death. Some people live a lifetime with a disability, and some a few weeks. Like death, it can visit you at any time. Unlike death, you live on with the disability. It is something that will affect us all. It is not something that only happens to someone else. Australians need to grasp this concept, particularly with an ageing population. However, embracing a concept does not automatically provide the wherewithal to make it happen. For example, desiring to provide environments with amenity for everyone is commendable, but knowing how to do it requires additional knowledge and training. Sharing of resources, experiences, and information within and between disciplines is also required. Researching new applications for assistive technology and environmental design can also assist the endeavour.

Much knowledge and information already exists in Australia. Many disability groups, and advocates for accessible and universal design have collected useful information from their experiences. However, there is nothing in place nationally to draw together the common threads, the new ideas and the collective wisdom of Australians. Furthermore, there is no national organisation that has dialogue with international organisations on the issues of access, universality and assistive technology, and we are therefore unable to utilise their collective knowledge to best advantage.

Australians would be well served by having a national organisation that can bring together all the good work being done by organisations and individuals in the fields of universal design, accessible environments and assistive technology. It can provide several interlinked services: operate a clearing house of information; provide education services; participate in research; contribute to policy development; raise community awareness; and it can provide a platform for international connections and communications. In short, an organisation such as this would be a vehicle for assisting people and organisations to design and develop the inclusiveness that the Disability Discrimination Act seeks to achieve.

Sooner or later we will all need accessible environments and assistive technology. Now is the time to begin in earnest.

RECOMMENDATIONS FOR AUSTRALIA

That a national centre for accessible environments, universal design and assistive technology be set up in Australia to provide information, education, research and input to policy development.

That the current practice of applying the intent of the Disability Discrimination Act continue as a means of ensuring progress towards inclusivity and equity.

That the access consulting profession be credentialed to ensure a minimum baseline of knowledge, to provide greater surety to consumers, and to provide more standardisation in the approach to access issues.

That universality of designs be promoted in Australia, not just accessibility. Universality is a concept devoted to enhancing lifestyles and opportunities. Accessibility is about including a marginalised group. The “feel-good” factor of the former is more attractive to the general public than the rules-based approach of the latter.

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Overview of the American Civil Rights Legislation

The civil rights legislation underpins the legislation for the rights of people with disabilities. The following explanation is reproduced in part from the CUD website (www.design.ncsu.edu:8120/cud)

Three major civil rights statutes were enacted during the Civil Rights Era from 1964 to 1968. In 1963, Dr Martin Luther King's refrain, "I have a dream" was a dream for a just and inclusive society. Late in 1963, Lyndon Johnson pressed the civil rights agenda forward. The enactment of the first of the major civil rights statutes, the Civil Rights Act of 1964, was a watershed moment in American history. Among its other ramifications, it established the statutory foundation on which Section 504 of the Rehabilitation Act of 1973 and later the Americans with Disabilities Act were constructed.

The Civil Rights Act of 1964 prohibited discrimination on the basis of race, religion, and national origin. However, the Act did not cover people with disabilities. Disability would not be linked to the mainstream of civil rights law until Section 504 of the Rehabilitation Act of 1973 was enacted.

In 1965, the second major anti-discrimination statute, the Voting Rights Act, was enacted, and three years later, the last of the major civil rights acts of the era, the Fair Housing Act was passed, but it did not include people with disabilities. In 1988, however, the Fair Housing Act was amended to add people with disabilities and families with children.

The Architectural Barriers Act of 1968 (ABA) was passed requiring that buildings constructed or altered by or on behalf of the state or federal governments be designed and constructed to be accessible to persons with disabilities. The ABA, while not initially effective established the foundation for accessibility in federally funded facilities.

The Architectural and Transportation Barriers Compliance Board, known as the federal Access Board, was established in 1973 under Section 502 of the Rehabilitation Act. As recognition of this grew within the federal government, the Access Board was strengthened. Eventually it assumed its current status as a key federal agency, establishing design and scoping standards for facilities covered by the Architectural Barriers Act, and by the Americans with Disabilities Act.

In 1990, President George Bush signed the Americans with Disabilities Act into law. It covers employment, requirements for state and local governments and service providers, telecommunications, and transportation.

Information taken from <http://www.adata.org/whatsada-history.html>

Principles of Universal Design

Universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

1. **Equitable Use:** The design is useful and marketable to people with diverse abilities.
2. **Flexibility in Use:** The design accommodates a wide range of individual preferences and abilities.
3. **Simple and Inuitive:** The use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
4. **Perceptible Information:** The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
5. **Tolerance for error:** The design minimizes hazards and the adverse consequences of accidental or unintended actions.
6. **Low physical effort:** The design can be used efficiently and comfortably and with a minimum of fatigue.
7. **Size and space for approach and use:** Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.

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