

How Long Must We Wait?: unmet promises of disability law and policy.

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All we really want to do

In the fall of 2000 we were invited to attend a prestigious international conference in Washington, 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 the transport system.

Before going on to document the discriminatory treatment we both faced, there are a number of preliminary points we wish to

make. To begin with, we recognize that using public transportation can be a difficult experience for all concerned, but we wish to exert that our experiences as disabled travelers go far beyond what the non-disabled traveler has to endure. Additionally, 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.

Finally, 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

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, patronised, 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 aeroplanes with their dignity and self-respect still intact. However I decided that the promise of the conference plus the opportunity to socialise 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.

The next hassle comes when I check in at Heathrow, London, one of the world's busiest airports. On arrival at check-in, 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 politely enquire as to what the rules are and 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 I prepare myself for the next hassle. 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 reasonably competently but I feel that it is hardly appropriate treatment for anyone to endure. It gets worse however, because the two men then try to dismantle my electric wheelchair and disconnect the batteries. I explain to them 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 travelling 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 recently, 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. Still we were now checked in so I prepare myself for the next battle.

This comes some two hours later when I am taken to the gate for boarding. I am told that I would 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 taken onto the jetty and down 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 re-arrange my clothing more appropriately.

I now settle down for the nine-hour flight but realise 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., suburbs. The rest of the passengers are disembarked onto 'mobile lounges'; Dulles International Airport does not have jetties. We are to be put on the last one with the remaining passengers but unfortunately while this lounge does have a chair to carry me off in there are no personnel to lift me. 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 aircraft seat arm and my clothing again comes adrift. I am placed onto the mobile lounge but another row breaks out as I must now be transferred into one of the fixed seats. Again this is eventually done but with no consideration for my dignity and privacy

and some threat to my health status as I feel that I am being thrown about by untrained and angry people.

The mobile lounge then does its job and takes us back to the terminal building where I expect my old, familiar and safe wheelchair to be waiting. It is not. 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 travelling with us; one of whom 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

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 at Dulles Airport, but still wishes to get together. I give him the name and address of the blues club, and 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. Absurdly enough, 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 that 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.

The ADA's promise of equal transportation access for disabled people has thus far failed to meet even minimal expectations. 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. On four separate occasions, MetroAccess failed to pick me up for rides to the airport, forcing me to spend \$40 on taxicabs for what should have been \$2.20 on the van.

Scheduling is notoriously bad. Drivers are frustrated by the impossible situation of rides that are scheduled too close together, and they often have no time for breaks during what can be twelve-hour shifts. Exhausted, frazzled drivers cannot help but be hazardous drivers.

Routing has little or no logic. Passengers are forced to share rides that take them in opposite directions than intended. Because MetroAccess is a ride-share service, its 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. This ostensibly saves people from having to ride all over the D.C. Metro area, picking up and dropping off other clients. 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.

Another time, I watched as the van drove right past the freeway exit to my home to drop off another client who lived ten miles down the road. Because of this, I rode an extra twenty miles unnecessarily.

The next time a van came to take me to school, I asked the driver, "Am I ride-sharing today? How long will I be on the van?" He checked his manifest, and then said, "Yes, you are ride-sharing, so you will probably be on the van about an hour and a half." I said, "I can't do that today. I just don't have the time. Please let me off the van." He refused to open the door. He said, "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.”

Drivers, dispatchers, and supervisors have rebuked me in this manner enough times to have me believe that their attitudes are a reflection of WMATA culture. 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 experiences with MetroAccess are not unique. When I ride-share with other disabled people, we often swap MetroAccess horror stories, establishing a pattern of abuses. At least five times that I know of, local television stations have run investigative pieces, providing video and audio documentation of how disabled people are treated by MetroAccess. One reporter filmed a faulty lift, with a wheelchair user in mid-air while the driver banged on the apparatus with a crowbar in a futile effort to force the lift to function. Once, I was on a van from D.C. to my home when the driver told me that he had to be careful which route he took because his reverse gear was broken and he had to route himself to avoid having to back up. Seat belts are often not in working order, and the ride in the back of the vans is so bumpy that your voice shakes when you try to talk.

Everyone interviewed had similar stories of being picked up hours late or not at all. A young woman reported that MetroAccess caused her to be very late to an interview for her first job. She did not get the job. Ironically, many times clients who have cancelled their rides in advance have found that the vans showed up at their doors anyway. This does not matter to MetroAccess subcontractors because they are paid per trip, whether or not clients actually ride. On top of that, clients are penalized for this practice because they are listed as “no-shows,” which goes against them on their MetroAccess records. Since so many MetroAccess riders have noted this practice, I wonder if cancelled rides are left on manifests on purpose.

Clients report spending up to half an hour on hold waiting for the dispatch office to answer phone inquiries about where their rides are. Many times, while they are inside a building, on hold for the dispatcher, the vans have come and gone without the riders knowing. Dispatchers refuse to send the van back because it is already on its way to the next destination. Dialysis patients have reported being dropped off at dialysis centers, and then abandoned even though their return ride home had been confirmed earlier. Wheelchair users report that their chairs were strapped down incorrectly, causing them

to slide around dangerously in the back of the van. In one of the television reports, the chief executive officer of WMATA responded with a note of surprise, as if he had never heard the complaints before. He said in a voice choked with mock sorrow, "We will do better." But the years go by and nothing changes.

Because I have had my booking either fall off or omitted from manifests so often in the past, 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. I ask her to check with the driver for his estimated time of arrival. She responds curtly,

“I *told* you it will be there any minute,” and disconnects the call before I can reply. I wait some more.

By six-thirty my anxiety has given way to frustration. I call the dispatch office 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 have never ceased to be amazed at the creativity of MetroAccess’s blunders, but this one takes the cake.

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 MetroAccess has spoiled my plans. I will not have my long-awaited, well-planned evening with my British colleagues. Once again, I have been disabled by MetroAccess system failures.

May the light shine on the truth someday

We have recounted our own personal experiences of interactions with 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. This is hardly surprising for an industry which pays almost no tax on the fuel it uses and which persuades governments to compensate it for an industry recession it created itself via over-pricing and poor service to customers. 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 experience 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.