TERI ADAMS'S EXTREMELY SUBJECTIVE VIEW: QUALITY OF LIFE FOR PEOPLE WITH DISABILITIES IN 2011

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"Disability" is extremely contextual

Anyone may be more or less "disabled" – in the sense of being functionally impaired – depending on the context/environment in which they placed.

- Physical environment
 - Architectural barriers
 - Climate
 - Availability of accessible public transportation
 - Availability of assistive technology
 - Durable medical equipment
- Legal Environment
 - Civil rights protections, e.g.
 - Americans with Disabilities Amendments Act of 2008
 - Section 504 of the Rehabilitation Act of 1973
 - Individuals with Disabilities Education Act, 1975

In 1957, these things were aspects of the context in which Teri was born:

Medical:

- Antibiotics have been available since WWII for general use
 - Skin infections which might have been lethal in an earlier time were, therefore, survivable
- Wheelchairs and Power wheelchairs were already in use; however doctor's were reluctant to prescribe them for patients who had some functional mobility, however difficult or painful
- Treatments for my disability were cosmetic the cause was genetic
 - In 1957, doctors did not understand the underlying cause of the skin disorder
 - They told my parents I would outgrow it

In 1957, these things were aspects of the context in which Teri was born:

Physical Barriers

In 1957 – none of these commonly existed:

- Curb cuts
- Widespread Braille signage
- Wheelchair ramps on buildings
- Accessible restrooms with handrails, etc.
- Power doors (on some grocery stores)
- No accessible busses or trains
- Visual fire alarms (horns & strobes) for the deaf

In 1957, these things were aspects of the context in which Teri was born:

Social/Legal:

In 1963, when Teri started school, children with disabilities were still routinely educated – if they were receiving public education at all – in segregated schools, or at home

 The Education for All Handicapped Children Act did not pass until 1975 (later renamed IDEA – Individuals with Disabilities Education Act)

Teri was in segregated programs until graduation from high school (in 1975) – although high school was semi-integrated. In high school, there was a special education "home room", but no services like we have now – extended time, note takers, etc.

- 1968 passage of Architectural Barriers Act (only applies to buildings built with federal funds)
- 1970 Ed Roberts and his group called the Rolling Quads, begins attending UC Berkeley



1971 – Ed Roberts and his friends begin the first Center for Independent Living in Berkeley, CA



- 1973 Section 504 of the Rehabilitation Act was passed
- (in essence, Section 504 says that any entity that receives federal funds must not discriminate on the basis of disability)
- 1975 Teri graduates from high school goes to Jr. Coll.
- 1977 April, Sit-ins staged by persons with disabilities to protest the failure of HEW to sign enacting rules and regulations of Section 504
- 1977 May, Section 504 regs are finally issued
- 1978 1988 ADAPT (American Disabled for Accessible Transit) protests, lobbies and gets arrested (for chaining themselves to busses) for accessible public transit

- 1978 Teri gets a job, and loses it because of the employer's concern that she would raise their health insurance costs
- 1980 Teri gets "grown up" job at Visa (no accommodation)
- 1984 Voting Accessibility for the Elderly and Handicapped Act
- 1986 Teri leaves Visa, because can't get promoted
- 1986 Air Carrier Access Act (prohibits discrimination)
- 1988 Fair Housing Amendments Act

1990 – Bush I signed the Americans With Disabilities Act (ADA 1990) – in part

Title I – Employment – Prohibits discrimination on the basis of disability in all aspects of employment, including hiring, promotion, and the provision of benefits

Title II – Part B, Public Transportation – Busses, commuter rail (here, CalTrain), Amtrak, light rail (VTA, Muni and BART, locally) can't discriminate in the provision of services on the basis of disability

- 1990 Bush I signed the Americans With Disabilities Act (ADA 1990) -- continued
- Title III Public Accommodations Private entities who own, lease....operate facilities such as stores, restaurants, movie theaters, doctors' offices, etc. Must not discriminate in the manner of provision of services; includes private entities that provide educational courses, examinations, etc.
- 1993 National Voter Registration Act
- 1993 Teri graduates from law school
- 1995 Teri is told that she didn't get a job because of disability

1996 – Telecommunications Act

2008 – Americans With Disabilities Amendments Act of 2008 – broadens definition of disability & discrimination; passed to legislatively strengthen the law, which had been weakened by "bad" court decisions

Physical Environment:

- More curb cuts than ever before, but not universal
- More accessible public transit, but still limited
 - No accessible taxis in most cities
 - Most busses are accessible, depending on where you live
 - CalTrain still has the 2 wheelchair per train rule if there are already 2 wheelchairs on the train when it comes to the station where you are waiting, they will leave you there to wait for the next train
 - Light rail is quite accessible in many places
 - Very uneven protocols for air travel, from flight to flight
 - Power chairs frequently damaged by airlines
- Renting a wheelchair accessible van is now possible, but is \$100/day, vs. \$15-and up for a car, and only through specialized company.

Physical Environment:

- Both Braille signage and horns & strobes are much more prevalent
- Today, you are likely to find an accessible restroom (with adequate turning space, handrails, etc., in places of public accommodation
 - But many of these accessible restrooms are used for storage by business owners, thus rendering them inaccessible
 - This is not true as true on the East Coast, in my limited experience
- Many more older buildings are retrofit to make entrances accessible
- Many stores have wider aisles so that a wheelchair can get through
 - Stanford's Bookstore has become much more accessible in the last 18 months or so
 - Stores like Macy's are still quite inaccessible in terms of getting to the merchandise

Physical environment (continued):

Restaurants still routinely have their tables too close together



Assistive Technology:

- Much greater variety of wheelchairs, both manual and power chairs
 - Problem: getting insurance to pay for the type of chair needed by the user and/or getting insurance to pay for more than one chair
- Hearing Aids are much more sophisticated
- Cochlear implants are commonplace
- Hip and knee replacements are, too
- Better technology available for severely disabled people
 - Cough Assist device, for people with breathing problems
 - Portable ventilators
 - Tilt-in-space wheelchairs for pressure-sore relief
 - Augmented speech devices
 - Speech recognition software

Very good news: The internet is a huge boon to people with disabilities.

- The internet and the access it provides to information and communication is a tremendous benefit to people with disabilities.
- Social interaction not formerly available to many people with severe disabilities is possible through the internet
- Access to information unprecedented
 - Enables people with disabilities to shop for devices and services
- The internet is a means for furthering the empowerment of people with disabilities in the same way that it is fostering the cooperation and information sharing of other disenfranchised groups

Bad News....

- Finding wheelchair accessible housing especially with a roll-in shower – is nearly impossible
- The durable medical equipment industry and how it interacts with health insurance is a nightmare
 - It is industry practice to mark-up everything at least 100%
 - Finding a competent and honest vendor is extremely difficult
- With all of the laws that have been passed, a passenger in a wheelchair can still be left on the platform – and nobody is bothered by that
 - What other protected class women, ethnic minorities, etc. would be told, only 2 of you may ride the train at the same time?
- Some employers, in response to the law, now put a list of physical requirements in their job descriptions, even for "desk jobs"

Good News....

The passage of the Americans With Disabilities Amendments Act of 2008 will lead to greater accessibility (through new regulations) in:

- Doctor's offices and medical facilities
- Hotels, reservation systems, and the travel industry

