

This article appeared in *Harvard Design Magazine*, Spring/Summer 2008, Number 28. To order this issue or a subscription, visit the HDM homepage at <<http://www.gsd.harvard.edu/hdm>>.

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Beyond the ADA

Respecting the Need of Many Disabled People for Assistance from Others
by **Thomas Spector**

SCENES FROM A PUBLIC RESTROOM

Here's a real-life situation I encounter frequently: My wife needs to use the public restroom, and she needs my assistance. Do we enter the women's or the men's room? Her fear of being grossed-out by the gauntlet of men splashing into the urinals on her way to the handicapped toilet (seated in her wheelchair, her eyes are at just *that* height) generally trumps my fear of encountering women gasping at the sudden appearance of a man in what they had every reason to assume was their domain. I am tempted to announce, "It's all right, girls, I'm a licensed professional!" but so far have preferred to keep as low a profile as possible as I remind myself that, strictly speaking, my entering the ladies' room is probably illegal — licensed or not.

I guide her past the lavatories, mirrors, and stalls to the back corner, hoping the handicapped stall will be unoccupied. If it is occupied, do we back all the way out, or do I wait with my head down? My wife's preference, though not mine, is to dress down whoever is inside — odds on it is not a handicapped person — to finish up and get the hell out: "Would you park your car in a handicapped spot? Then

why is your ass parked on the handicapped toilet?"

Bless the airports that have made family restrooms plentiful and easily found despite the fact that they aren't required (except *McCarran International* in Las Vegas, where the family restroom is generally held hostage by loafing janitorial staff). For my wife and me, the idea that the disabled are like everyone else, made independent once the barriers are removed, is absurd. Mobile, yes. Independent, no. Activities that would not otherwise be possible now are — Hooray! — but not without assistance. Our reality places us in good and plentiful company: The census reports that difficulty going out due to disability affects some twenty million Americans.¹ How do all these people cope? They get help.

FROM ETHICS TO TECHNIQUE

These days, the United States kicks major ass when it comes to incorporating the disabled into public life. With the Americans with Disabilities Act a mere sixteen years old, its integration into contemporary thinking is so complete that its provisions no longer feel the least bit remarkable. Interpreting the ADA has

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passed out of the confusing realm of the ethical — “What *should* we do?” — into the reassuring realm of the merely technical: “This is *how* we do it.” Its quick acceptance owes much to its successfully equating the refusal to provide access for the disabled with the immorality of racial discrimination, thereby incorporating the big club of 1960s civil rights, with its special abhorrence of any suggestion of *Plessy v. Ferguson* separate-but-equal, into its ethical and legal arsenal. Unwillingness to tolerate second-class status for the disabled is something anyone could grasp, and the provision for equality in public restrooms was understandably a particularly sensitive subject in this regard.

My anecdote suggests that this big club is sometimes unwieldy, ignoring important differences between race and disability. Was its passage into technique perhaps a little too hasty?

The percentage of the population reporting a disability involving problems with self-care (as defined by the 2000 Census) jumps from 1.8% of the population aged sixteen to sixty-four to 9.5% of those over 65. Obviously, as people age, their disabilities accrue. The Census also relates that problems with self-care are always accompanied by other disability-related issues.² That the aging constitute such a large part of the disabled population clashes with the image of the cussedly independent young person who just happens to have had an injury or accident — wheelchair-bound but otherwise in good health and able to lead a productive life. No. The aging disabled get out in the world with assistance from others.

Here is where the idealized view of disability underlying the Americans with Disabilities Act shows its shortcomings. By treating disability on a par with skin color or other irrational reasons to discriminate, the ADA pointedly ignores the fact that the largest single segment of the disabled population cannot operate autonomously in society even with curbs, ramps, grab bars, audio alarms, and the like. That the autonomous disabled are often the most noticeable only underscores their exceptionality. It should come as no surprise that some of the pro-

visions emanating from the mistaken assumption of independence among the disabled would be suboptimal in many instances.

The most obvious example of a faulty assumption leading to less-than-ideal results is the provision for handicapped stalls in public restrooms. The fact that a huge proportion of people with disabilities require assistance when going out of their homes means that many a disabled person in public will have an assistant. This assistant is quite often of the opposite sex, as spouses assist each other, parents help their children, and the like. This sort of familial assistance is much to be preferred to institutional or paid-for assistance.

Here is the rub: By idealizing the model of a disabled person as someone made autonomous by the barrier removal and therefore discouraging the provision of separate-but-equal “family care” bathroom facilities (because their provision doesn’t lessen the number of handicapped facilities needed in same-sex restrooms), the ADA ultimately ensures that the uncomfortable social situation of people of the opposite sex in same-sex restrooms will play out repeatedly. This situation is made worse by the standard (and recommended) placement of the wheelchair-accessible stall in the farthest reaches of large public same-sex bathrooms and the complete disregard in the planning standards of the likely presence of two people in that stall.

This faulty assumption plays out in other situations as well. Consider the requirements for bathing facilities. Anyone in a wheelchair knows that the real danger lies in the transfers — the moment of “taking air” between wheelchair and toilet, for example. So why require that showering occur in a shower room separate from the toilet for the sake of equality? This attack on separate-but-equal is even more counterproductive than the public restroom requirement because it increases physical danger. Were showering while on the toilet permitted in lieu of a separate shower stall, self-cleaning would be made easier and the number of transfers, made doubly dangerous under wet conditions, would be reduced.

FROM TECHNIQUE TO CREATIVITY

As the Surgeon General observes, attitudes are changing³; but underlying assumptions about what the disabled need and deserve are resistant. Now that the ADA is firmly ensconced in American culture, perhaps we can risk a more nuanced approach to public accommodation. Let us get past the fiction that most disabled people would be fully independent “if only. . . .” It does everyone a disservice. By recognizing that many disabilities require a rethinking of facility design as much as equal access, the country would be closer to destigmatizing the dependency that accompanies so much disability and to providing an enriching and enjoyable public life to a new wave of disabled people. Now, if someone could just explain what that silly little bar behind the toilet accomplishes. . . . □

NOTES

1. Judith Waldrop and Sharon M. Stern, *Disability Status: 2000*. Census 2000 Brief, Census Bureau, March 2003. “Census 2000 counted some 49.7 million people with some type of lasting disability.” And from the Surgeon General: “22.6% of 45 to 54 year olds have some form of disability; 44.9% of 65 to 69 year olds have some form of disability; and 73.6% of those 80 years and older have some form of disability.” *The Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities*, <www.surgeon-general.gov/library/disabilities/calltoaction/factsheet-whatwho.html>.
2. Waldrop and Stern. “Among people with difficulty going outside the home, 81.5% indicated at least one other measure of disability. The disability most likely to be linked to multiple conditions was the self-care measure — 97% of people who marked this type of condition also reported one or more of the other measures of disability.”
3. Richard H. Carmona, Surgeon General of the United States, and Jennifer McCabe, Editor, “Improving the Health and Wellness of Persons with Disabilities: A Call to Action,” *American Journal of Public Health*, November 2005, 1883. “The perception of disability is in transition. With the recognition that disability is not an illness, we increasingly emphasize continuity of care and the relationship between a person with a disability and the environment at the physical, emotional, and environmental levels. Today, fifty-four million Americans — more than 20% of us — are living with at least one disability.”