

Students do not have to be disabled to benefit from greater access to teaching materials. Furthermore, UID also allows faculty the freedom to be more flexible in achieving course goals and expectations. Too often, faculty assume that their methods of delivery are synonymous with the student's achievement of course goals. On the contrary, student learning goals are often more easily achieved when the possibilities of diverse learning styles and methods are explored.

The application of UID principles enables all students to have access to a greater range of teaching materials and this access to teaching materials, in turn, is one way to transform educational structures and create more equitable and socially just learning environments. Quite simply, UID is about social justice and transforming oppressive social relationships. As such, it is consistent with the missions of multicultural education and social justice education.

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## The Social Construction of Disability

*Susan Wendell*

... I see disability as socially constructed in ways ranging from social conditions that straightforwardly create illnesses, injuries, and poor physical functioning, to subtle cultural factors that determine standards of normality and exclude those who do not meet them from full participation in their societies. I could not possibly discuss all the factors that enter into the social construction of disability here, and I feel sure that I am not aware of them all, but I will try to explain and illustrate the social construction of disability by discussing what I hope is a representative sample from a range of factors.

### SOCIAL FACTORS THAT CONSTRUCT DISABILITY

First, it is easy to recognize that social conditions affect people's bodies by creating or failing to prevent sickness and injury. Although, since disability is relative to a person's physical, social, and cultural environment, none of the resulting physical conditions is necessarily disabling, many do in fact cause disability given the demands and lack of support in the environments of the people affected. In this direct sense of damaging people's bodies in ways that are disabling in their environments, much disability is created by the violence of invasions, wars, civil wars, and terrorism, which cause disabilities not only through direct injuries to combatants and noncombatants, but also through the spread of disease and deprivations of basic needs that result from the chaos they create. In addition, although we more often hear about them when they cause death, violent crimes such as shootings, knifings, beatings, and rape all cause disabilities, so that a society's success or failure in protecting its citizens from injurious crimes has a significant effect on its rates of disability.

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The availability and distribution of basic resources such as water, food, clothing, and shelter have major effects on disability, since much disabling physical damage results directly from malnutrition and indirectly from diseases that attack and do more lasting harm to the malnourished and those weakened by exposure. Disabling diseases are also contracted from contaminated water when clean water is not available. Here too, we usually learn more about the deaths caused by lack of basic resources than the (often life-long) disabilities of survivors.

Many other social factors can damage people's bodies in ways that are disabling in their environments, including (to mention just a few) tolerance of high-risk working conditions, abuse and neglect of children, low public safety standards, the degradation of the environment by contamination of air, water, and food, and the overwork, stress, and daily grinding deprivations of poverty. The social factors that can damage people's bodies almost always affect some groups in a society more than others because of racism, sexism, heterosexism, ageism, and advantages of class background, wealth, and education.

Medical care and practices, traditional and Western-scientific, play an important role in both preventing and creating disabling physical damage. . . . Lack of good prenatal care and dangerous or inadequate obstetrical practices cause disabilities in babies and in the women giving birth to them. Inoculations against diseases such as polio and measles prevent quite a lot of disability. Inadequate medical care of those who are already ill or injured results in unnecessary disablement. On the other hand, the rate of disability in a society increases with improved medical capacity to save the lives of people who are dangerously ill or injured in the absence of the capacity to prevent or cure all the physical damage they have incurred. Moreover, public health and sanitation measures that increase the average lifespan also increase the number of old people with disabilities in a society, since more people live long enough to become disabled.

The pace of life is a factor in the social construction of disability that particularly interests me, because it is usually taken for granted by non-disabled people, while many people with disabilities are acutely aware of how it marginalizes or threatens to marginalize us. I suspect that increases in the pace of life are important social causes of damage to people's bodies through rates of accident, drug and alcohol abuse, and illnesses that result from people's neglecting their needs for rest and good nutrition. But the pace of life also affects disability as a second form of social construction, the social construction of disability through expectations of performance.

When the pace of life in a society increases, there is a tendency for more people to become disabled, not only because of physically damaging consequences of efforts to go faster, but also because fewer people can meet expectations of "normal" performance; the physical (and mental) limitations of those who cannot meet the new pace become conspicuous and disabling, even though the same limitations were inconspicuous and irrelevant to full participation in the slower-paced society. Increases in the pace of life can be counterbalanced for some people by improvements in accessibility, such as better transportation and easier communication, but for those who must move or think slowly, and for those whose energy is severely limited, expectations of pace can make work, recreational, community, and social activities inaccessible.

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Pace is a major aspect of expectations of performance; non-disabled people often take pace so much for granted that they feel and express impatience with the slower pace at which some people with disabilities need to operate, and accommodations of pace are often crucial to making an activity accessible to people with a wide range of physical and mental abilities. . . .

Much of the public world is also structured as though everyone were physically strong, as though all bodies were shaped the same, as though everyone could walk, hear, and see

well, as though everyone could work and play at a pace that is not compatible with any kind of illness or pain, as though no one were ever dizzy or incontinent or simply needed to sit or lie down. (For instance, where could you rest for a few minutes in a supermarket if you needed to?) Not only the architecture, but the entire physical and social organization of life tends to assume that we are either strong and healthy and able to do what the average young, non-disabled man can do or that we are completely unable to participate in public life.

A great deal of disability is caused by this physical structure and social organization of society. For instance, poor architectural planning creates physical obstacles for people who use wheelchairs, but also for people who can walk but cannot walk far or cannot climb stairs, for people who cannot open doors, and for people who can do all of these things but only at the cost of pain or an expenditure of energy they can ill afford. Some of the same architectural flaws cause problems for pregnant women, parents with strollers, and young children. This is no coincidence. Much architecture has been planned with a young adult, non-disabled male paradigm of humanity in mind. In addition, aspects of social organization that take for granted the social expectations of performance and productivity, such as inadequate public transportation (which I believe assumes that no one who is needed in the public world needs public transportation), communications systems that are inaccessible to people with visual or hearing impairments, and inflexible work arrangements that exclude part-time work or rest periods, create much disability.

When public and private worlds are split, women (and children) have often been relegated to the private, and so have the disabled, the sick, and the old. The public world is the world of strength, the positive (valued) body, performance and production, the non-disabled, and young adults. Weakness, illness, rest and recovery, pain, death, and the negative (devalued) body are private, generally hidden, and often neglected. Coming into the public world with illness, pain, or a devalued body, people encounter resistance to mixing the two worlds; the split is vividly revealed. Much of the experience of disability and illness goes underground, because there is no socially acceptable way of expressing it and having the physical and psychological experience acknowledged. Yet acknowledgement of this experience is exactly what is required for creating accessibility in the public world. The more a society regards disability as a private matter, and people with disabilities as belonging in the private sphere, the more disability it creates by failing to make the public sphere accessible to a wide range of people.

Disability is also socially constructed by the failure to give people the amount and kind of help they need to participate fully in all major aspects of life in the society, including making a significant contribution in the form of work. Two things are important to remember about the help that people with disabilities may need. One is that most industrialized societies give non-disabled people (in different degrees and kinds, depending on class, race, gender, and other factors) a lot of help in the form of education, training, social support, public communication and transportation facilities, public recreation, and other services. The help that non-disabled people receive tends to be taken for granted and not considered help but entitlement, because it is offered to citizens who fit the social paradigms, who by definition are not considered dependent on social help. It is only when people need a different kind or amount of help than that given to "paradigm" citizens that it is considered help at all, and they are considered socially dependent. Second, much, though not all, of the help that people with disabilities need is required because their bodies were damaged by social conditions, or because they cannot meet social expectations of performance, or because the narrowly-conceived physical structure and social organization of society have placed them at a disadvantage; in other words, it is needed to overcome problems that were created socially.

Thus disability is socially constructed through the failure or unwillingness to create ability among people who do not fit the physical and mental profile of "paradigm" citizens. Failures of social support for people with disabilities result in inadequate rehabilitation, unemployment, poverty, inadequate personal and medical care, poor communication services, inadequate training and education, poor protection from physical, sexual, and emotional abuse, minimal opportunities for social learning and interaction, and many other disabling situations that hurt people with disabilities and exclude them from participation in major aspects of life in their societies.

For example, Jongbloed and Crichton point out that, in Canada and the United States, the belief that social assistance benefits should be less than can be earned in the work force, in order to provide an incentive for people to find and keep employment, has contributed to poverty among people with disabilities. Although it was recognized in the 1950s that they should receive disability pensions, these were set, as were other forms of direct economic help, at socially minimal levels. Thus, even though unemployed people with disabilities have been viewed by both governments as surplus labour since at least the 1970s (because of persistently high general rates of unemployment), and efforts to increase their employment opportunities have been minimal, they are kept at poverty level incomes based on the "incentive" principle. Poverty is the single most disabling social circumstance for people with disabilities, since it means that they can barely afford the things that are necessities for non-disabled people, much less the personal care, medicines, and technological aids they may need to live decent lives outside institutions, or the training or education or transportation or clothing that might enable them to work or to participate more fully in public life.

Failure or unwillingness to provide help often takes the form of irrational rules governing insurance benefits and social assistance, long bureaucratic delays, and a pervasive attitude among those administering programs for people with disabilities that their "clients" are trying to get more than they deserve. . . .

I do not want to claim or imply that social factors alone cause all disability. I do want to claim that the social response to and treatment of biological difference constructs disability from biological reality, determining both the nature and the severity of disability. I recognize that many disabled people's relationships to their bodies involve elements of struggle that perhaps cannot be eliminated, perhaps not even mitigated, by social arrangements. But many of the struggles of people with disabilities, and much of what is disabling, are the consequences of having those physical conditions under social arrangements that could, but do not, either compensate for their physical conditions, or accommodate them so that they can participate fully, or support their struggles and integrate those struggles into the cultural concept of life as it is ordinarily lived.

### CULTURAL CONSTRUCTION OF DISABILITY

Culture makes major contributions to disability. These contributions include not only the omission of experiences of disability from cultural representations of life in a society, but also the cultural stereotyping of people with disabilities, the selective stigmatization of physical and mental limitations and other differences (selective because not all limitations and differences are stigmatized, and different limitations and differences are stigmatized in different societies), the numerous cultural meanings attached to various kinds of disability and illness, and the exclusion of people with disabilities from the cultural meanings of activities they cannot perform or are expected not to perform.

The lack of realistic cultural representations of experiences of disability not only contributes to the "Otherness" of people with disabilities by encouraging the assumption that their lives are inconceivable to non-disabled people but also increases non-disabled people's fear of disability by suppressing knowledge of how people live with disabilities. Stereotypes of disabled people as dependent, morally depraved, superhumanly heroic, asexual, and/or pitiful are still the most common cultural portrayals of people with disabilities. Stereotypes repeatedly get in the way of full participation in work and social life. For example, Francine Arsenault, whose leg was damaged by childhood polio and later by gangrene, describes the following incident at her wedding:

When I got married, one of my best friends came to the wedding with her parents. I had known her parents all the time I was growing up; we visited in each other's homes and I thought that they knew my situation quite well.

But as the father went down the reception line and shook hands with my husband, he said, "You know, I used to think that Francine was intelligent, but to put herself on you as a burden like this shows that I was wrong all along."

Here the stereotype of a woman with a disability as a helpless, dependent burden blots out, in the friend's father's consciousness, both the reality that Francine simply has one damaged leg and the probability that her new husband wants her for her other qualities. Moreover, the man seems to take for granted that the new husband sees Francine in the same stereotyped way (or else he risks incomprehension or rejection), perhaps because he counts on the cultural assumptions about people with disabilities. I think both the stigma of physical "imperfection" (and possibly the additional stigma of having been damaged by disease) and the cultural meanings attached to the disability contribute to the power of the stereotype in situations like this. Physical "imperfection" is more likely to be thought to "spoil" a woman than a man by rendering her unattractive in a culture where her physical appearance is a large component of a woman's value; having a damaged leg probably evokes the metaphorical meanings of being "crippled," which include helplessness, dependency, and pitifulness. Stigma, stereotypes, and cultural meanings are all related and interactive in the cultural construction of disability. . . .

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## **Go to the Margins of the Class**

### ***Disability and Hate Crimes***

*Lennard J. Davis*

With great ceremony, the press reported the February 1999 conviction of white supremacist John William King for the kidnapping and murder of James Byrd, Jr., who had been chained to a truck in Jasper, Texas, dragged two miles, and dismembered. Likewise, the conviction of coconspirator Lawrence Russell Brewer in September 1999 seemed to imply that justice had been done. If justice in a broader sense is to be served, however, another

fact of the case deserves attention. Byrd was not only black and the victim of race hatred; he was also disabled. The press has noted this so casually that few people realize it; those who do, including myself, found out that Byrd was severely arthritic and subject to seizures. This information was ferreted out only after extensive searches of news reports.

Indeed, I myself was uncertain that Byrd was a person with disabilities. I recalled reading, on the day the crime was first reported, that a disabled African American had been brutally murdered. Since I was interested in disability, the article caught my eye. Yet when the story reappeared days, weeks, and months later, Byrd was simply referred to as African American. Almost all the news stories contained this simplification. Indeed, when I decided to write a piece on the subject for *The Nation*, I at first thought I might have made an error in thinking that Byrd was a person with disabilities. When I went to the library to look up the articles on microfilm, I found that the *New York Times* mentioned only twice, in the first two reports, that Byrd was a person with disabilities. Any newspaper story I checked tended to follow that pattern.

Initially, I wanted to write this story as an op-ed piece for the *New York Times*. An acquaintance who is on the editorial board of the paper read my initial article and responded in a somewhat condescending and negative way. He asked me if I seriously thought that race could be equated with disability, whether the history of lynching and slavery could be meaningfully equated with occasional violence against people with disabilities. The editors for both these progressive journals saw race as the primary category and disability as a poor third cousin of race. Their assumption was that violence toward a person of color with disabilities is primarily the result of the color and much less the result of the disability.

But disability is hardly a minor category. Approximately 16 percent of Americans have a disability and, as such, they comprise a significant minority group with an inordinately high rate of abuse. According to the Center for Women's Policy Studies, disabled women are raped and abused at a rate more than twice that of nondisabled women. The risk of physical assault, robbery, and rape, according to researcher Dick Sobsey, is at least four times as great for adults with disabilities as for the general population. In February 1999, for example, a mentally retarded man in Keansburg, New Jersey, was abducted by a group of young people who tortured, humiliated, and assaulted him. In March 1999, advocates for another mentally retarded man filed a lawsuit against a group of Nassau County, New York, police officers who beat him while he was in custody.

People with disabilities and deaf people report that they are routinely harassed verbally, physically, and sexually in public places. In private institutions or group homes, they are often the prime victims of violence and sexual abuse; in their own homes, they are subjected to sexual abuse, domestic violence, and incest, preyed upon by family members, family "friends," and "caretakers." So the question remains, why is American society largely unaware of or indifferent to the plight of people with disabilities? Is it because as an ableist society, we do not really believe that disability constitutes a serious category of oppression? Whenever race and disability come together, as in the King case, ethnicity tends to be considered so much the "stronger" category that disability disappears altogether.

As a society, we have long been confronted by the existence of discrimination against people of color. Students pour over the subject of race in their textbooks and read the work of multicultural writers in high school and college. Martin Luther King Day and Kwanzaa raise our consciousness, and the heroic tales of people like Rosa Parks inspire us.

But while we may acknowledge we are racist, we barely know we are ableist. Our schools, our textbooks, our media utterly ignore the history of disability; the dominant culture renders invisible the works of disabled and deaf poets, writers, and performance artists. The closest we have come to a national media engagement is the 1998 six-part NPR radio series *Beyond Affliction* and a few references to deafness in the TV series *ER*. Motion

pictures still largely romanticize or pathologize disability; there is not much else to make the experience of 16 percent of the population come alive realistically and politically.

Yet 72 percent of people with disabilities are unemployed, and their income is half the national average. Among working-age adults with disabilities, the poverty rate is three times that of those without impairments. One-third of all disabled children live in poverty; and despite the Americans with Disabilities Act, a judicial backlash has been under way ever since its passage in 1990. From 90 to 98 percent of discrimination cases brought under the ADA by people with disabilities have been lost in court. . . .

Anita Silvers notes this fact when she writes: "the courts tend to implement prohibitions against discrimination so as to favor paradigmatic members of the protected class. In doing so, they propel individuals whose experiences diverge from those of the class's prototypes, but who are equally at risk, to the class's margins." Thus when disability meets race, disability is propelled to the margins of the class.

From a legal perspective, one wants to make sure that members of a historically unprotected class receive proper justice and consideration under the law. Thus in America, women and minorities have been the focus of antidiscrimination law. There has been much cultural work done to make it acceptable at the end of the millennium for such groups to have public respect and sympathy. Countless novels, movies, and plays have accomplished this goal over the course of the twentieth century. It is unimaginable that a film could be made now that would present African Americans, Native Americans, or women as members of a deservedly subordinate, disenfranchised group. Thus the courts will, in the most obvious cases, uphold the right of members of such groups to redress wrongs in housing, employment, discrimination, and so on.

However, disability occupies a different place in the culture at this moment. Although considerable effort has been expended on the part of activists, legislators, and scholars, disability is still a largely ignored and marginalized area. Every week, films and television programs are made containing the most egregious stereotypes of people with disabilities, and hardly anyone notices. Legal decisions filled with ableist language and attitudes are handed down without anyone batting an eyelid. . . . Newspapers and magazines barely notice the existence of disability and largely use ableist language and metaphors in their articles. In other words, disability may be the last significant area of discrimination that has not yet been resolved, at least on the judicial, cultural, and ethical levels, in the twentieth and twenty-first centuries. . . .

So when it comes to violence against people with disabilities, several factors intervene. Although many states have statutes that describe disability in a list of categories that are protected under hate crime legislation, the actual enforcement of such policies may be muted by the intersectionality I have been describing. The Violent Crime Control and Law Enforcement Act of 1994 defines a hate crime as one "in which the defendant intentionally selects a victim, or in the case of a property crime, the property that is the object of the crime, because of the actual or perceived race, color, religion, national origin, ethnicity, gender, disability or sexual orientation of any person." . . .

Tellingly, though, a distinction is often made in this legislation. For example, previously under California's hate crime law, a murder committed because of the victim's race, color, religion, ancestry, or national origin could bring the death penalty or life in prison without parole. However, the maximum penalty for a murder based on gender, sexual orientation, or disability was twenty-five years to life in prison. A new bill signed in September 1999 increases the maximum in those latter categories to life in prison without parole. Federal efforts to prevent hate crimes, however, are now restricted to race, color, religion, and national origin.

Several U.S. senators have sponsored legislation to extend protections to gender, disability, and sexual orientation. But this idea ultimately did not pass into law and, even if

it had, hate crimes based on disability are unlikely to carry as stringent a penalty as crimes based on hate for race, color, religion, or national origin. . . .

But how do we determine, in any philosophical sense, that one kind of identity is more important than another? Historically, although the United States was founded on a separation of church and state, religion has been seen as a "holy" category certainly higher in status than, for example, one's sexual orientation; race, so embroiled in the nation's history, must be more important than something like disability; and so on—the arguments are based more on ad hoc judgments about the viciousness of different kinds of prejudice than on any principle one can articulate. This seems to be the same unreflective influence that gives priority to race over gender or disability in the intersectionality argument.

We can see this contradiction in another arena. The FBI is required to keep track of hate crimes. It has produced a report that found that of the 8,049 incidents of hate crime reported to police in 1997, 12 were motivated by bias based on disability; of these, 9 were based on the victim's physical condition and 3 were based on the victim's mental condition. These numbers seem shockingly low when compared to other studies such as Dick Sobsey's tabulations. Sobsey also notes that when a person with disabilities is a victim of crime, it tends to be a violent crime rather than a property crime.

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Indeed, I am sure that when it comes time for the FBI to list the report on Byrd, they will file it under racial hate crime rather than a disability-related crime. Also, many of the crimes against people with disabilities will simply be seen as ordinary rather than hate crimes. So the rape or murder of a mentally ill resident of a sheltered facility will be seen as a rape or murder, not as one motivated by the status of the person involved. Indeed, one of the arguments used by opponents of hate crime legislation, particularly as it applies to gender or disability, is that crimes such as rapes will have to be investigated by the FBI, putting an undue burden on that organization. Since such crimes are daily occurrences, and since it could be argued that rape itself is a hate crime against women, the FBI will be taxed to the utmost in trying to detail all these acts of violence.

Intersectionality argues that individuals who fall into the intersection of two categories of oppression will, because of their membership in the weaker class, be sent to the margins of the stronger class. What these statistics suggest is that the category of disability, while a weak one to judges or legislators, is a powerful one to those who seek to victimize. Rather than minimizing an identity, victimizers are drawn to the double or triple categories of race, gender, and disability. Each of these categories enhances the opportunity for hate and the likelihood that the crime will go unnoticed, unreported, or disbelieved. For example, the Center for Women's Policy Studies reports that virtually half of the perpetrators of sexual abuse against women with disabilities gained access to their victims through disability services, and that caregivers commit at least 25 percent of all crimes against women with disabilities. In other words, the dependency of such women, compounded by their lower economic status, ethnicity, and diminished mobility or ability to communicate to authorities, is an enticement to victimizers.

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The point here is that the general climate of ableism makes it comfortable for us to regard systematic violence against people with disabilities as accidental. Could one claim that the university's policy of negligence toward students with disabilities, especially after being forewarned, was a willed act of violence? The consciousness of the general public and the legal system would have to undergo a dramatic change for the truth of such a claim to be obvious.

Likewise, the definition of "hate" has to change as well. One of the reasons there is resistance to calling attacks against people with disabilities "hate" crimes is because the general ideology toward people with disabilities rules out hate as a viable emotion. In our

Cyr said he started to have bad dreams, had difficulty keeping a job and has had trouble finding work for the past few years because employers seemed turned off that he's disabled from his military service.

He felt constantly on edge, spent too much money, drank too much and started smoking marijuana because it was the only thing that seemed to help him keep calm.

Cyr signed up for the Army Reserve but eventually resigned because he had trouble following assignments and didn't feel comfortable around his fellow soldiers. His officers, he said, urged him to get tested for PTSD. He was diagnosed by VA [Veterans Administration] doctors four years ago.

Cyr said he takes medication the VA doctors prescribed, including antidepressants and pills to help him sleep, and goes to psychiatric therapy sessions. The treatment helps, he said, especially when he feels the need to talk about an incident in Iraq that's been bothering him.

"I get so emotional, but I keep it to myself because I feel like I'd be depressing people," he said. "Veterans need someone to relate to without bothering their friends and family."

Cyr has since gotten married and now has two children. He says his wife is "a special person to put up with someone who has panic attacks, can't sleep at night, won't sleep in the bed and just has serious rage sometimes."

On a day-to-day basis, Cyr believes he's functioning better, but said he also realizes there's no "cure" for PTSD, just treatment and strategies for managing it better.

"Things are OK, but every day is really affected by it," he said. "Post-traumatic stress is invisible. It's an injury to your emotions and it's lifelong, forever lasting."

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## On the Spectrum, Looking Out

Jess Watsky

My world was changed for the better by a big, technical book, called *The Diagnostic and Statistical Manual of Mental Disorders*. Looking back, I never expected to be at odds with the very publication that opened my eyes to my mind's inner workings. When I was thirteen, flipping through the pages of my mother's copy of the DSM IV-TR, the name of one "mental disorder" stuck out like a sore thumb, enticing peals of laughter from me and my friends—*Asperger's Syndrome*. Though it shouldn't have been a surprise, coming from a child whose idea of fun with friends was to look through psychology diagnostic manuals, it was both a shock and a comfort to be diagnosed a year later from that very same section of the very same book.

Because "Asperger's" was described, my world was a little more transparent. It unveiled some of the intricacies in my own mind that had seemed unexplained. The clearly defined obsessions, ranging from a six-month flirt with marbles to a three-year binge on molecular gastronomy, now had a name—"repetitive interests and obsessions"—and my childhood propensity for big words and inability to comprehend idioms was no longer simply a foible of my past. Even if I didn't feel like Rain Man, I now had a name for the many quirks to my mannerisms that had plagued me for the last decade and a half. Needing to go to three

different grocery stores to make sure I hadn't missed any interesting foods was no longer the end result of anxiety, but a starting point, an issue I had the tools to confront and stop in its tracks before I ran my car out driving to other states in search of unique food.

I know this diagnosis has soothed people's fears as well as my own, and served as a jumping ground to plot their next move, just as it has certainly done for me. My Asperger's diagnosis helped me to learn about boundaries and conversational norms, allowed me to rethink my inner-arguments and has given me time to pause and think about what I say, rather than reverting to a repetitive monopoly of a conversation. Without the diagnosis, it felt as though I had been working with a consistently clever, yet idiosyncratic machine for many years without having even a manual or well-versed technician alongside to help me troubleshoot.

That's not to say that things were immediately easier for me. I still struggled in school, unable to foster interactions with peers. When I explained to many of them that I wasn't just strange and had, in fact, an inability to interact as they did, my confession was met with derision. It is a cruel twist of irony that a disorder centering on a social hindrance would don the incredibly clunky—but for me, helpful—moniker of "Asperger's Syndrome." But now, for its new edition, *The Diagnostic and Statistical Manual of Mental Disorders* plans to eliminate the diagnosis of Asperger's Syndrome as a stand-alone condition, and to merge it into the more generalized description of Autism Spectrum Disorder (ASD). This puts me at odds with the very publication that opened my eyes to my mind's inner workings. Although I have prospered through many hardships both socially and academically as a result of working with my Asperger's Syndrome, the new approach may mean that I may not fit the diagnostic criteria for ASD and will not be eligible for related health insurance coverage needs. In fact, in reviewing the proposed diagnostic standards for ASD, for all intents and purposes I fit only three of the four criteria necessary for a diagnosis. Certainly, that is sufficient evidence of a dysfunction, yet not enough (one must meet all four) to receive a diagnosis of ASD. In the eyes of the American Psychiatric Association, as of May 2013 I will cease to have Asperger's Syndrome or ASD.

With this change, thousands of successfully and well-functioning Asperger's-diagnosed adults, and many, many more undiagnosed children, will lose a diagnosis and a name to put to their unique, curious lives. In May of 2013, I am anxiously anticipating another life-changing event, because in that same month I will be graduating from college with a bachelor's degree in History. Although my mental abilities always foretold a future with college, I'm sure that if I hadn't been diagnosed with Asperger's Syndrome, I wouldn't have excelled so well and taught myself to fluently navigate the turbulent university atmosphere. I wouldn't be writing this; thinking about this, realizing my dreams without this key component of my brain.

The changes in the DSM-IV are only one variable in the complicated equation of what it means to have Asperger's Syndrome. The rest is up to society to read words like mine and listen to the people they interact with and understand them. Meet us at face value without forcing us to make eye contact or expect an immediate adherence to your social customs and understand that we are people with different wiring, but similar desires. It is not solely a dream of the Aspergian to want to live in a world where they are accepted and appreciated for their unique talents. People automatically perceive disabilities to be something automatically visible or detectable from their conceptions of "normal" people. It hurts to be told we blend seamlessly into the world, but that we are shunned because of how we work inside. Capture that feeling and meet us with compassion and know that reaching out to us is important. We are not emotionless robots, nor are we calculating sociopaths as some would believe. Nor should we be pigeonholed into relationships with other Aspergians solely because the rest of the world has overlooked us. We have just as much of a right to coexist in society as anyone else, and have the potential to change the



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world in amazing ways. Regardless of formal status or legal terminology, there are still thousands of people in this world with Asperger's Syndrome, whose identities have been enhanced and helped with such a diagnosis, and we will not vanish simply because our name has gone away. We cannot disappear. We are people, too.

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## How to Curse in Sign Language

*Ashley and Deborah*

... When I arrived at Starbucks, I saw Deborah, sitting alone, not drinking any coffee. She appeared to be in her midforties and was wearing tapered jeans and white shoes. She looked like a nurse who was exhausted after working the night shift. Raising a child like Ashley, I thought, she must feel fatigued all the time. She sat in her chair like someone who had been standing for years.

I sat down and introduced myself. There was no small talk. Deborah started right in with her story. She had grown up in a rural setting, in Virginia Beach, in a middle-class Catholic home. The household income was just enough to meet the family's needs. Deborah had a twin brother, and their extended family was large. Family gatherings often included more than seventy-five people, "nudging and talking over each other," she told me. "I loved it."

... The problems continued even after the birth of their son, Chip. Finally, after months of drama and upheaval, Deborah—with the support of an Episcopal minister—filed for divorce, went to court, and eventually got custody of her son.

Ashley came into Deborah's life through an announcement posted at a local United Methodist church not long after she and her young son had moved to Richmond. Deborah was trying to rebuild her life. She was working in computers, a career she had set in motion when she was still a cop, and completed her bachelor's degree in computer science while working full-time. She was also taking an exercise class at the aforementioned church. One day, she arrived early, thirty minutes before her class began. To kill time, she stood around reading various postings on the church bulletin board. The tip of a yellow piece of paper, burlled under the rest, caught her eye, and she uncovered an announcement from the United Methodist Family Services. This organization was holding an adoption information program for people who might consider "challenging" adoptions. She decided to attend the session just to "see what the group had to say."

... After the meeting, Deborah signed up for a nine-week training session followed by what is known as a "home study." This training was a prerequisite for going any further in the adoption process. According to Deborah, "the leaders of the training didn't pull any punches and shared the very difficult things involved in the adoption of special-needs or older children." Many of these children would need lifelong care. Many would require advanced medical supervision at home. Many would have emotional problems. But after each session, Deborah "felt even more strongly about adoption as an option." Most people

## What I'd Tell That Doctor

Jason Kingsley

I am Jason Kingsley. I am now almost twenty-nine years old. Ten years ago I wrote an article for *Count Us In: Growing Up with Down Syndrome*, a book that Mitchell Levitz and I wrote. That article is about a confrontation I would have had with the obstetrician—if I had met him—about what he said years ago to my parents when I was born.

What I would say to the obstetrician is the same as what I would say to the parents of any newborn child who is born with a disability and who is born with Down syndrome.

The things I said ten years ago are true now and even more so.

When I wrote that article, I was still in school. But now I am on my own. I live in a house with two other roommates. We have very little supervision. We do our own cooking; we do our own shopping and cleaning. We do take public transportation. And above all else, our house is accessible to the community and to our work.

All three of us work in the community. I happen to work in the White Plains (New York) Public Library. My roommate Raymond works at PETCO, a pet store, and has been there for six years. And Yaniv works at an Armonk (New York) law firm.

In conclusion, I hope you will look at this article that I wrote ten years ago. Then get *Count Us In: Growing Up with Down Syndrome* and read the whole thing. You will find it very essential, inspiring, and helpful.

Here is my article:

When I was born, the obstetrician said that I cannot learn, never see my mom and dad and never learn anything and send me to an institution. Which I think it was wrong.

Today we were talking about if I could see my obstetrician and talk to him, here are things I would say . . .

I would say, "People with disabilities *can learn!*"

Then I would tell the obstetrician how smart I am. Like learning new languages, going to other foreign nations, going to teen groups and teen parties, going to cast parties, becoming independent, being . . . a lighting board operator, an actor, the backstage crew. I would talk about history, math, English, algebra, business math, global studies. One thing I forgot to tell the obstetrician is I plan to get a academic diploma when I pass my RCTs . . .

I performed in "The Fall Guy" and even wrote this book! He never imagined how I could write a book! I will send him a copy . . . so he'll know.

I will tell him that I play the violin, that I make relationships with other people, I make oil paintings, I play the piano, I can sing, I am competing in sports, in the drama group, that I have many friends, and I have a full life.

So I want the obstetrician will never say that to any parent to have a baby with a disability any more. If you send a baby with a disability to an institution, the baby will miss all the opportunities to grow and to learn . . . and also to receive a diploma. The baby will miss relationships and love and independent living skills. Give a baby with a disability a chance to grow a full life. To experience a half-full glass instead of the half-empty glass. And think of your abilities not your disability.