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Whether their perpetrators realize it or not,
Disability Awareness Days send

THE WRONG MESSAGE

By Valerie Brew-Parrish

Hey, Hey, Hey, it's Disability Awareness Day! Everyone gets a chance to see what it's really like to have a disability! Yank out those blindfolds, grab cotton to stuff in your ears, and plop yourself in a wheelchair to navigate around an obstacle course! To get the most out of Disability Awareness Day, it is important to try almost all the disabilities on for size.

Now it is time to tie one of your arms behind you so you can fully appreciate a paralyzed limb.

No doubt about it, life with a disability is a tragedy! Why these poor gimps, blinks, and others would be better off dead! They are so courageous and yet pitiful as they go about their daily routines. Yep, I'm so glad it is their fate and not mine . . .

Sadly, these are the misconceptions that the public holds about those of us who live with disabilities. Disability simulations do nothing but reinforce these negative stereotypes about persons with disabilities.

Like the Jerry Lewis Telethon, disability simulations should be abolished. The disability community should be as outraged by disability simulations as they are over the negative implications of telethons. Overwhelming feelings of pity well up in those who simulate a disability -- and pity does not equate with dignity. Disability simulations rob persons with disabilities of their dignity and self respect.

Simulations are phony. To "simulate" means to assume the mere appearance of -- without the reality. The reality is this: nondisabled persons can never understand what it is like to have a disability. Jumping in a wheelchair for a few minutes, wearing a blindfold, and stuffing cotton in one's ears does not make a person understand life with a disability.

People who have never been disabled who simulate a disability are often terrified. Many of the "simulators" even cheat a little. Haven't we all observed a person standing

up in their wheelchair in order to lift the chair over a curb? They breathe a collective sigh of relief knowing full well that their charade will soon come to an end and their momentary disability will gratefully vanish.

Agencies purportedly serving disabled clients frequently advocate disability simulations, with fancy brochures encouraging the public to assume a disability with blindfolds and wheelchairs. The pamphlets gleefully expound the theory that disability simulations are useful for teaching family members and others what the person with a disability is really experiencing.

What these rehab professionals fail to realize is that the public does not have the coping skills or strategies developed by people who actually have disabilities.

This point was clearly illustrated a few years ago when airline personnel decided to blindfold themselves to test evacuation procedures in case of an airline crash. The results were disastrous. Naturally. The airline staff had no training in mobility or orientation. Therefore, they erroneously concluded that blind persons could never safely evacuate a plane. Nothing could be further from the truth.

When I'm disoriented in a dark place, I let my blind husband lead the way! The National Federation of the Blind has long argued that disability simulations are destructive. Other disability groups should follow their lead and speak out against these sordid attempts to empathize with us by becoming gimp for a day.

For several years, I was employed at a large university that sponsored an annual "Disability Awareness Day." Despite protests from students and staff with disabilities, the nondisabled sponsors of the event continued the spectacle.

I was told by participants that I was an inspiration because I coped so well with my disability. Others told me they would rather be dead than live with a disabling condition. The participants of the simulation debacle now looked at me with pity. In their eyes, I was no longer on an equal basis with them; they felt superior because all of their limbs were in proper working condition.

Regrettably, it seems every annual celebration of the passage of the Americans with Disabilities Act, every disability awareness event, is combined with a tasteless display of disability simulations. In many instances, persons with disabilities are actually participating and perpetuating these contemptible attempts to make the public aware.

Awareness Days can be beneficial if they are done properly; it is important for the public to meet with persons with disabilities and to interact with us. Why not have people who use wheelchairs discuss obstacles and the need for accessibility? Deaf persons can demonstrate sign language skills, and blind persons can show proper travel techniques. The public needs to know we exist; that we are professionals, parents and homeowners just like them.

But disability simulations need to die a quick death. There are more effective and positive ways to educate the public. Come on folks, we can do a better job getting our messages across. We do not need people to pretend they have disabilities and simulate our disabilities to understand us. All of us need to demand to be treated with dignity. When disability simulations become extinct, perhaps the flood of pity will dry up and be replaced with respect.

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The Wrong Message -- Still

by [Valerie Brew-Parrish](#)

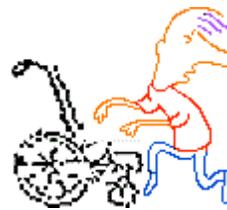
HEY, HEY, HEY it's Disability Awareness Day! Still. Even in the 21st century!

Schools, government agencies, and sometimes, deplorably, gimp groups, are still offering the public "try on a disability" programs -- exercises in which nondisabled people are blindfolded, put into wheelchairs or given earplugs to "simulate" having a disability.

When I first wrote my article, [The Wrong Message](#), back in 1997 for the Ragged Edge, I never imagined the stir it would cause. I am proud that the article has made people think about the harm simulations can do.

I still consider simulations an atrocity perpetuated -- mostly -- by nondisabled professionals. Disabled folks are sometimes involved though, as well.

I don't know who dreamed up the concept of "disability simulations" but they have been around for a mighty long time. My lifelong friend, Michael A. Winter, now the Director of Civil Rights for the U.S. Department of Transportation, first exposed me to the shameful practice. Michael and I were classmates at a segregated school for crips and met in 6th grade. We attended the same university. As undergrads, Michael formed a group called Wheelchair Action. When the Rehabilitation Institute at Southern Illinois University sponsored a disability simulation, Michael and members of his group stormed into the classroom and tried in vain to halt the fiasco.



My muscles started to hurt from sitting all day.

-- Joliet (IL) Central High School student.

Professionals who are nondisabled rarely stop to listen to the people who live with disabilities. I was proud of Michael for trying to get people to understand how destructive these simulations can be.

Nondisabled people usually come away from disability simulations

- thinking life is a tragedy for persons with disabilities,
- thanking the good Lord they are not saddled with a disability
- or falling prey to the "amazing" syndrome: "Ohhhhh just lookie at what disabled people can do! They're better than us at (getting around in the dark, popping wheelies, reading hand signs . . .)"

When I wrote "The Wrong Message," I was angry. My daughter Tara had come home from school in tears. It was Disability Simulation Day at Greenwood High. Blindfolded students were being led around by sighted students, others were bumping into walls. The

students were terrified of their newly created disabilities. Some had told Tara they thought persons with disabilities had horrible lives; a few thought they might be better off dead.

School personnel knew that both Tara's parents had disabilities. She was quizzed about her home life: did she have to take care of us? was she resentful? Were we a burden to her? Did she miss out on having a childhood? Sometimes the questions were implied; at other times they were quite direct.

Her answers always warmed my heart and brought tears to my eyes. She told them she had been taught from infancy to accept people of all colors, creeds, and disabilities. She told them about going along with her parents to conferences all over the country. She told them about meeting Ed Roberts when she was little, and, later, meeting Justin Dart. She reminded them that she participated in soccer and ballet and had even attended a Neil Diamond concert.

Although Greenwood High often needed substitute teachers, they refused to hire my husband Rick, because he's blind. Rick holds a teaching certificate and an advanced degree. He applied to the school system to work as a substitute, but was never called to Greenwood High. Many a day Tara would come home to tell us that her school had been unable to locate enough substitute teachers for the day.

After two years of this, Rick filed a complaint with the U.S. Department of Education Office of Civil Rights, noting as well in his complaint that the school had hired a phys ed teacher who held no teaching certificate whatsoever.

The investigator found merit in his complaint (school administrators had held meetings to debate letting a blind person teach), and Rick was awarded back pay for all the days it was determined he would have been able to teach had he not been excluded -- close to \$5,000.

I contacted the school's psychology teacher once and tried to get Disability Simulation Day stopped. It was a lost cause. She liked having Disability Simulation Day featured in the local newspaper, and saw no need for me or my husband -- or anyone from our local independent living center -- to come to her classroom to talk with the students.

Every March, the Indiana Governor's Planning Council for People With Disabilities does a really stupendous job providing materials for people in celebration of Disability Awareness month. Their posters are excellent, as are their public service announcements.

But their "Disability Awareness Activities" booklet, one of their handouts, is horrendous.

Here are a couple of excerpts from their publication. You decide:

All Thumbs (physical disabilities, group activity)

Materials: masking tape, raisins, nuts, pudding.

Activity: Sometimes people with physical disabilities don't have good muscle control. With masking tape, tape together the fingers of the participant's weaker hand, leaving only the thumb free. Give each participant a cup of raisins or a dish of pudding to eat using only that hand. Divide participants into pairs. Let one in each pair feed the other a dish of pudding. Trade places.

Discussion: How did you feel during these experiments? Did you find ways to overcome the problems of eating when you had less control of your hands? How does it feel to be fed by someone else?

"Thick Hands"

Materials: thick socks, shirts, sweaters, shoes, beads, string and ruler.

Activity: Some people have trouble with fine motor coordination. This is because their muscles are weaker, and they need more time and practice to learn how to move. To help participants understand this condition, have them put a pair of thick socks on each hand and try to tie shoes, button a shirt and string beads. Tie a ruler between the students' ankles so that their legs are stiff and apart from each other. Have them walk down the hall and back, slowly. How would they feel if people laughed or stared at them or imitated the way they walked?

Discussion: Some people who have these kinds of difficulties have mental retardation. Their muscles are weaker and their coordination is poor. But not everyone with these difficulties has mental retardation. Discuss this assumption. Can you assume that someone who can't use his or her hands has mental retardation?"

Because I have paralyzed arms, I never wear tie shoes, a simple fashion decision that compensates for my inability to tie shoes. There's nothing demeaning about it. There are many such things students could learn. The activities detailed above, though, cannot help but suggest helplessness. They evoke pity and disgust. The raisins and pudding dribble out of participants' mouths and get splattered across their clean faces. Being fed, they can't help but conclude, is a demeaning experience.

Even the exercises' titles are offensive. "All Thumbs" is a cliché -- for clumsiness. Suggesting that someone who can't use their hands has mental retardation, even if made ostensibly to prove it wrong, seems to beg the question. Would it not be more instructive to show a physics video of Stephen Hawking?

On May 5, in Joliet, IL, Joliet Central High School journalism students, turned loose on a "Disabled for a day" article in the local newspaper, had this to say: "My muscles started to hurt from sitting all day... although I was in physical pain, the worst part as knowing that many people have to endure this pain on a daily basis for the rest of their lives."

And, "I briefly felt how it would feel to be wheelchair bound for life. I couldn't keep the tears in my eyes."

And, "People with mental disabilities don't comprehend and learn like others, but they're carefree. I would love to be carefree at times."

And, "Trembling and shaking, I took my first steps blind...I felt like I was in a small, dark room... At the end of the day, I took off the blindfold. I was so grateful because so many people do not have the option of taking off the blindfold."

These were the honest feelings the students got from participating in an Awareness Day. Is this the message we really want to send about living with a disability?

I AM BAFFLED AS TO WHY nondisabled people see a need to simulate a disability in order to understand our situation. Across our nation in February, we celebrate Black History Month. Is it necessary for people with white skin to paint their faces black to better understand this minority? Should heterosexuals be asked to experience homosexuality so we are not homophobic?

Should I expect to be able to teach someone how to drive a car, diaper and dress a baby and make the bed with their feet as I do? Am I amazing? No; I am just living my life.

We, the people who live with disabilities, we who have so long advocated for being treated as full members of society, must reclaim our dignity and say "No!" to simulations. I long for the day when disability simulations are dumped into the trash cans of oblivion.

WHAT CAN BE DONE to help the nondisabled masses understand the disability experience?

Talk to us and ask us questions. Ask persons who have had a disability from birth (or a longtime disability) to come to your class or organization.

Read publications written BY persons with disabilities: [Ragged Edge](#), [Mouth](#) magazine, [Braille Monitor](#).

There are some really excellent books out there, too. Here are some of my favorites:

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- [Reflections from a Different Journey What Adults with Disabilities Wish All Parents Knew](#) by Stanley D. Klein & John D. Kemp
- [Make Them Go Away Clint Eastwood, Christopher Reeve & the Case Against Disability Rights](#) by Mary Johnson
- [Moving Violations : War Zones, Wheelchairs, and Declarations of Independence](#) by John Hockenberry
- [By Trust Betrayed](#) by Hugh Gregory Gallagher
- [FDR's Splendid Deception](#) by Hugh Gregory Gallagher
- [Don't Laugh At Me](#) by Steve Seskin and Allen Shamblin / Illustrations by Glin Dibley. Afterword by Peter Yarrow (ages 4-8)
- [No Pity](#) by Joseph P. Shapiro
- [Awakening To Disability Nothing About Us Without Us](#) by Karen G. Stone
- [Extraordinary People With Disabilities](#) by Deborah Kent. Short essays profile 48 famous people -- John Milton, Helen Keller, FDR, Tom Cruise -- who have disabilities.

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Awareness Days:

Some Alternatives to Simulation Exercises.

A staple of 'Awareness Days' is the simulation exercise: Put a nondisabled person in a wheelchair. Tie on a blindfold. But these tactics are often criticized as sending [the wrong message](#). What are the alternatives? Chapman University's [Art Blaser](#) has a few suggestions.

- 1.** Talk about doing simulations -- without doing them. What are the kinds of experiences that only a nondisabled person simulating a disabled one would have? What are simulations designed to do? Is that a desirable objective? Do they really accomplish that objective? Why, or why not?
- 2.** Listen to a disabled person -- one in your neighborhood, your class, around school. Ask them about their life -- not about medical aspects of the disability. When we compare what we've found out, we'll have heard not from a couple of "experts" but from enough people to realize that there are differences and similarities. Then compare the findings with information about disabled people in the U.S. from the [U.S. Census](#) and Harris surveys done for the [National Organization on Disability](#).
- 3.** Read a book or watch a video about a person with a disability. John Hockenberry's [Moving Violations](#) is a good book; [When Billy Broke his Head](#) is a good video, so is [Kiss My Wheels](#). Consider whether the experiences depicted are typical or atypical and why.
- 4.** Try *not* doing something: If a restaurant isn't accessible, try not going there. If a restroom isn't accessible, don't use it. If there's space to do so, see a movie from the "wheelchair section." If you go with friends, don't suggest or restrict where they sit.
- 5.** Some people with disabilities insist that there are many positive aspects to the experience of being disabled. Discuss why they say this.
- 6.** Survey neighborhoods: cars parked over driveways, unleashed dogs, sidewalks and curb-cuts, color contrast on stairs (people with low vision need this), branches that can hit a blind person. Note audible cues (such as horns honking).
 - Find a curb cut. Is the "cut" flush with the street at the bottom, or is there still a lip? Is the curb cut broken? Would it be easy or hard to use it in a wheelchair? Are cars parked in front of it, making it unusable?

- Look at the entrance to your favorite coffee shop or bookstore. Is it flat? Is there a small step? Are there lots of steps? What would need to be altered to make it accessible? Sometimes there's a loading ramp in back a disabled person can use. What do you think about having to enter that way?
- Go to a local clothing shop in the mall. Notice how much space there is between racks of clothes. What would this be like for someone who is blind or who has a mobility disability?

7. Find out what confronts a family traveling and living in motels or hotels. Visit a local hotel. Find out where TDD/TTY phones are and how you would find one if you were deaf. Find out what choices you'd have if you needed to get a wheelchair accessible room for a family of 6. If you were a wheelchair user, would you be able to use the bathroom in the room? Or the shower?



There
are
positive
s to
being disabled!

8. Search for a personal assistant. Find out what the job entails. Local newspapers will contain ads. The local center for independent living is a source of other leads. Some people work through companies listed in the Yellow Pages. Without misrepresenting yourself, find out what they charge and what they pay. Would you take such a job? Why or why not?

9. Doing the things above may reinforce your idea of just of how bad it is being disabled.. Using a 5x8 card, anonymously write down reactions you'd have if you were to wake up as a member of the other gender. How would you react? How would your family, your friends and your neighbors react? Now share this with the others in your group doing this exercise. Did it turn out that a lot of your preconceptions were just plain silly?

10. Even obviously artificial pretending can be lots of fun. There are three exercises you may want to do. Try these at home:

- Bob Cummings, who used to be executive director of the Center for Independent Living in Orange Co., CA., would ask his audiences to shut their eyes. He'd then ask if they'd stopped thinking about their next meal, their appointments with friends, or what they'd be doing an hour from now. Of course they hadn't! His point was that an awful lot remains the same whether you are blind (as he was) or not. The example he liked to give of what he couldn't do was skeet shooting -- which he'd never done (nor had any desire to do) before he was blind, either.
- "Stuffing your mouths with marshmallows will produce speech like mine," Blaser tells his students. "Does that then mean you will then know how I think, too? If so, then I can go home. You could, too, but you wouldn't do well in the class."

- A simulation with practical effect is the closed fist that can't open round door hardware, but can open lever type door handles. The open hand will open either type.

In the exercises above, some disabilities are covered more than others. Why might that be?

People will often talk about disability in terms of what people can't do. When might this lead to dubious conclusions?

Art Blaser chairs the Political Science Dept. at Chapman University. His most recent article for Ragged Edge was ["Changing the meaning of 'disability'."](#)