

WATCHDOG

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Reporting on Disability with Sensitivity, not Sensationalism

When people with disabilities are portrayed as only heroes or victims, it's harder to address the issues that affect them

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No reporters had talked to Clayton Berg, one of the workers with intellectual disabilities in a \$240 million abuse case, before Dan Barry wrote “The ‘Boys’ in the Bunkhouse” *Nicole Bengiveno/The New York Times/Redux*

One day back in the spring of 2013, New York Times reporter Dan Barry was looking for a topic for “This Land,” his column about American life, when he came across a newswire story about a labor case involving a group of men with intellectual disabilities. The facts of the case: 32 men with disabilities, working for the same wage for 35 years, \$240 million in damages. “What the heck are we talking about here?” Barry recalls thinking. The men had been rescued from living in squalor and working in abusive and exploitative conditions at a turkey processing plant in tiny Atalissa, Iowa. They had spent decades working for just \$65 a month, living in a house infested with bugs and infused with a rank smell. Roaches fell from the ceiling as they ate. They slept on dirty mattresses and used metal trashcans to catch water from melting snow on the roof.

Barry called the lawyer on the case to find out more—and also to ask about speaking with the men. The lawyer’s response was surprising: Not a single reporter had ever asked to speak with the men before.

When the turkey processing plant bunkhouse was closed down in 2009, some local media in Iowa reported the news. But by then the men had already been relocated to other places around the state and the country. Some coverage included interviews with one of the men’s sisters. The Des Moines

Register published photos and videos of what it described as the “house of horrors” where the men had lived. Barry felt the story was too compelling and had too many unanswered questions, and he was intent on giving the men a voice.

He began by tracking down the men and methodically conducting interviews. First, he got a third-party introduction from a caretaker. When he initially met the men in person, he didn’t take any notes; they just talked. The second time he met them, he had a notebook. The third time there were cameras. Along the way, he verified information by circling back to caretakers and the attorney on the case. The result: “[The ‘Boys’ in the Bunkhouse](http://www.nytimes.com/interactive/2014/03/09/us/the-boys-in-the-bunkhouse.html) (<http://www.nytimes.com/interactive/2014/03/09/us/the-boys-in-the-bunkhouse.html>),” a multimedia report centered around Barry’s 7,000-plus word column, in which he painted a vivid portrait of the men themselves and the horrible conditions in which they had lived. An accompanying short documentary, “[The Men of Atalissa](http://www.nytimes.com/video/us/10000002757071/the-men-of-atalissa.html) (<http://www.nytimes.com/video/us/10000002757071/the-men-of-atalissa.html>),” a collaboration between the Times and PBS’s POV, was produced by Barry and his colleague, video journalist Kassie Bracken.

“I just wanted him to be a guy in a bus,” Barry says of his depiction of Clayton Berg, one of the men, on his way to work at his new job after leaving Atalissa. “The mundane nature of that is kind of extraordinary because of where he came from.”

Before Dan Barry asked, no journalist had sought to interview the men at the heart of a \$240 million lawsuit

Barry didn’t want the men’s former circumstances or their disabilities to distract from the fact that they were, first and foremost, human beings—something that seems obvious but, too frequently, seems forgotten in depictions of people with disabilities. Stereotypes and even prejudices about disability persist, and those stereotypes can creep into media coverage in the form of clichés. People with disabilities are viewed as heroes for accomplishing ordinary tasks, as victims, or—in cases of violent crime involving the mentally ill—as villains.

“There are two extremes,” says Gary Arnold, president of [Little People of America](http://www.lpaonline.org/) (<http://www.lpaonline.org/>), which advocates for the approximately 35,000 Americans with dwarfism, a condition that results in short stature and can lead to a number of health complications. “One extreme is portraying people with disabilities as people who are helpless and deserving of pity. That reinforces the stigma of disability as something that is bad and that would need to be changed. On the other extreme, you have the overly heroic portrayal of disability, where the person is portrayed as a superhero for doing things that a non-disabled person does on an everyday basis.”

There are nearly 57 million Americans with disabilities (nearly 1 out of every 5 people), [according to U.S. Census data](https://www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html) (<https://www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html>), with conditions ranging from the physical—blindness, deafness, paralysis—to the mental and psychological, including depression and anxiety. Most newsrooms don’t have reporters specifically focused on covering people with disabilities and many activists and support organizations say Barry’s sensitive, non-sensationalistic story is the exception rather than the rule. Even research on stories depicting people with disabilities is hard to come by.

Arnold, of Little People of America, can cite plenty of examples of coverage that people with disabilities consider offensive. He says Little People of America stopped making itself available as a source to The Huffington Post, for example, because the publication consistently placed stories with their interviews in the website’s “[Weird News](http://www.huffingtonpost.com/weird-news/) (<http://www.huffingtonpost.com/weird-news/>)” section. A search of the word “dwarf” on the site does turn up a number of headlines under that section: “[Dwarf Stripper Kat Hoffman Finds Love With Army Sergeant](http://www.huffingtonpost.com/2015/01/24/kat-hoffman-dwarf-stripper_n_6534644.html) (http://www.huffingtonpost.com/2015/01/24/kat-hoffman-dwarf-stripper_n_6534644.html),” “[Jahmani Swanson Is ‘Michael Jordan of Dwarf Basketball’](http://www.huffingtonpost.com/2014/12/29/-jahmani-swanson_n_6390982.html) (http://www.huffingtonpost.com/2014/12/29/-jahmani-swanson_n_6390982.html)” and “[Ritch Workman, Florida Lawmaker, Says Yes To ‘Dwarf-Tossing,’ No To Gay Marriage](http://www.huffingtonpost.com/2011/10/25/ritch-workman-dwarf-tossing_n_1025112.html) (http://www.huffingtonpost.com/2011/10/25/ritch-workman-dwarf-tossing_n_1025112.html).” Huffington Post spokeswoman Lena Auerbuch says the publication has “spent years developing a respectful relationship with the little people community,” though she acknowledged that stories about people with dwarfism that involve pop culture and fringe entertainment “do sometimes appear in our Weird News vertical, a vibrant community that examines counterculture.” In September 2015, The Huffington Post added a [disability news section](http://www.huffingtonpost.com/news/accessibility/) (<http://www.huffingtonpost.com/news/accessibility/>) to its website after pressure from advocates.

“What the disability community wants is attention to our issues,” Arnold says: access to health care, education, and government services, as well as the right not to face discrimination.

The Americans with Disabilities Act (<http://www.ada.gov/>) (ADA), passed in 1990, was designed to address precisely these issues. The ADA protects against discrimination on the basis of disability in employment, public services, transportation, and telecommunications. It defines disability as anything that interferes with an individual’s reasonable access to and accommodations in public places and services, including the ability to be employed and educated. Many journalists are unaware of just how wide this definition is. That, argues Beth Haller, journalism professor at Towson University in Maryland and author of two books on people with disabilities and the media, has limited coverage. “People just presumed that all the [ADA] covered is people who are deaf, blind, or use wheelchairs,” she says. “If the media understood how broad the definition was, that would help.”

Crucially, this definition of disability covers a diverse list of physical conditions, ranging from AIDS and migraine headaches to diabetes and complications from pregnancy, and also includes people with a range of mental and psychological disorders, certain learning disabilities, and intellectual disabilities, like those of the Atalissa men in Barry’s story. For “The ‘Boys’ in the Bunkhouse,” The New York Times team was careful to portray the men as real people who could help tell their own stories. Photographer Nicole Bengiveno and videographer Kassie Bracken spent about a year reporting the piece—researching, interviewing, photographing, and traveling to the different states where the men had settled in the time since the house closed down in 2009.



Juli Windsor completed her first Boston Marathon in 2014. Andy Laub

One of the key elements of their reporting was patience. Initially, they were barred from taking photos or video. As the team earned trust, the restrictions were eased. “We had to put the story together in a very sensitive way,” says Bengiveno. “It was like detective work, meeting the men and learning their stories. Sometimes, there were scrapbooks, and we looked at their pictures. We saw them over and over again, because we had to get to know them.” Bengiveno spent time with the men without Barry, working to take photographs as unobtrusively as possible. She captured the men watering the garden, riding the bus, making dinner—mundane domestic tasks they were denied during their lives in Atalissa.

To tell the men’s stories, Barry relied on his own reporting as well as public records, court documents, and testimony by an expert who interviewed all the men for the trial. Sometimes, a caretaker helped him communicate with the men, since some of them had hearing and speech impediments. The greatest challenge was nailing down the timeline of events, since the men’s developmental and intellectual disabilities—which impacted their reasoning and learning—often affected their sense of time. Barry says there was “no trick or special approach” to his reporting; he just talked to the men and asked them to tell their stories.

That approach—treating people with disabilities as sources, not just subjects—is what advocates want more of. The National Center on Disability and Journalism (<http://ncdj.org/>) (NCDJ) offers interviewing tips (<http://ncdj.org/resources/reporters/interviewing-tips/>) and a style guide

[\(http://ncdj.org/style-guide/\)](http://ncdj.org/style-guide/) for reporters covering disability. One of the most important things to remember when interviewing those with intellectual disabilities: Speak directly to the person you are interviewing, not their companion, and regard that person as the expert.

Also crucial is to not group all people with similar disabilities together, assuming how one person's disability affects their life is universal for all people with the same handicap. This, according to journalist Mike Porath, extends to writing about the disability. "Ask the individual who is being interviewed how he or she would like to be referred to in the story," says Porath, who founded [The Mighty \(http://themighty.com/\)](http://themighty.com/), a media company focused on sharing stories—many from a first-person perspective—of people with diseases and chronic illnesses. "One person may want to be called 'autistic' and another may want to be called 'a person with autism.' It should be up to the interviewee, not the interviewer."

Porath conceived the idea for The Mighty after his young daughter was diagnosed with Dup15q syndrome, a rare chromosome disorder. He wanted a single community where people with disabilities could share their experiences and connect with others. "There is a lot of medical information on the Web, but not nearly enough stories of personal experiences that can often be far more helpful, insightful, or empowering," says Porath, who worked for ABC, NBC, and The New York Times before founding The Mighty in 2014. "We need more stories from the perspective of individuals with disabilities."

The Mighty has produced more than 6,000 stories since it launched, including ones that have been syndicated in outlets such as The Huffington Post and Yahoo.

Members of the disabled community are increasingly telling their own stories elsewhere, too. Martyn Sibley, a Brit with spinal muscular atrophy who uses a wheelchair, decided to do that by [writing a blog \(http://martynsibley.com/\)](http://martynsibley.com/) about accessible tourism, technology, health, and personal relationships. He co-founded and writes for the online magazine [Disability Horizons \(http://disabilityhorizons.com/\)](http://disabilityhorizons.com/) as well as The Huffington Post and The Independent. "For true inclusion," Sibley says via e-mail, "we do need inspiration stories, but also everyday achievers who 'happen' to have a disability."

Juli Windsor, a Boston-based physician's assistant, considers herself an everyday achiever who happens to have a disability. In 2013, she e-mailed Boston Globe reporter David Abel to pitch [a story about her effort \(https://www.bostonglobe.com/metro/2013/04/13/dwarfs-outrun-expectations-and-send-message/7T3OgXHJnKp7AMBqowveqO/story.html\)](https://www.bostonglobe.com/metro/2013/04/13/dwarfs-outrun-expectations-and-send-message/7T3OgXHJnKp7AMBqowveqO/story.html) to become the first dwarf to run the Boston Marathon. "My initial intent was that I wanted there to be more stories of people with disabilities being out there doing worthwhile things," says Windsor. However, she stressed that she didn't want to be depicted as a runner who was somehow overcoming her disability or defying expectations by logging those 26.2 miles.

"I do not view my life as a life of challenges and limitations," Windsor says. "That's not how I want to be portrayed."

At the time, Abel was spending a year as a Nieman Fellow at Harvard University, but decided to work on [a documentary about her \(https://vimeo.com/65437032\)](https://vimeo.com/65437032) for a class. He was waiting at the finish line on April 15, 2013 when two bombs went off. The race was halted soon after the explosions, and about 5,700 participants were never able to cross the finish line—including Windsor. She was less than a mile away from the end.

Abel was part of the Globe team that won a Pulitzer Prize for its coverage of the bombing, but he came back to Windsor for [a *Runner's World* article in 2014 \(http://www.runnersworld.com/newswire/juli-windsor-leads-the-way\)](http://www.runnersworld.com/newswire/juli-windsor-leads-the-way). She ran the marathon for a second time, with Abel by her side. The pair crossed the finish line together, holding hands. The experience was grueling for Windsor, not just physically—at 3-foot-9, she takes roughly twice as many steps as the average runner, and, since dwarfs often suffer problems with their spines, she can experience significant back pain after long runs—but mentally, as well. Running past the spot where she was stopped the year before, Windsor had tears in her eyes, remembering the collective and personal trauma stemming from the bombings; her mother, who had been standing near the finish line, sustained face injuries and a shattered shoulder when she was trampled in the tumult.

It was this characterization of Windsor, as a Bostonian personally impacted by the bombing and persevering despite the heightened physical and mental obstacles, that Abel focused on in his article. For Abel, Windsor's stature was only part of the reason he wanted to write about her. "If there's a compelling story, my sense is we shouldn't focus on the disability as much as the person and what their story is," he says. "The disability is just a piece of that."

“I do not view my life as a life of challenges and limitations. That’s not how I want to be portrayed.”

—Juli Windsor, Boston Marathon runner

That appears to be more challenging when addressing people with mental disabilities. “In recent years, the time you see mental illness covered the most is when there’s a violent act,” says Shannon Heffernan, a broadcast journalist with WBEZ radio in Chicago who has reported extensively on the subject. “I think mental illness and violence are linked in people’s minds. What that does is it further stigmatizes mental illness.”

This was certainly the case in August after journalists Alison Parker and Adam Ward, of Roanoke, Virginia’s CBS affiliate WDBJ, were shot and killed during a live television broadcast. Soon after he fled the scene, the gunman uploaded a cell phone video of the incident, recorded from a first-person perspective, to his social media accounts, which were suspended soon after. Hours later, he shot and killed himself after a car chase with police officers.

Many stories about the gunman focused largely on his mental state. One CNN story alleged that his mental state was unknown, yet still referenced mental illness and firearms control in the same paragraph. The gunman had a history of conflicts with former colleagues, and media conjecture about mental instability was never verified; the killer was never clinically diagnosed with a mental disorder. The portrayal of shooters as “crazy” perpetuates stereotypes of mental illness as being to blame for a whole array of societal problems, including gun violence, taking culpability away from other possible factors—including how easy it is to acquire a weapon in the U.S.



The Americans with Disabilities Act turned 25 years old in 2015, the year of the inaugural Disability Pride Parade in New York Seth Wenig/Associated Press

There is little training for journalists on how to avoid stigmas. Sarasota Herald-Tribune reporter Carrie Seidman decided to address the situation head-on. In “[The S Word: The Stigma of Schizophrenia](#),” Seidman—who is the Florida paper’s dance critic, but occasionally does special projects—wrote two separate stories about two different men navigating their mental illnesses with help from their mothers. The first of those two narratives was Seidman’s own story, written in the first person, about her son, Keaton, and his “jagged journey to stability,” starting from his first psychotic break, in college, until his diagnosis today, as a man in his early 30s who is able to live a relatively independent and productive life.

Six short vignettes about people with schizophrenia and their family members

(<http://schizophrenia.heraldtribune.com/Chapter/4>), who were all granted anonymity because the stigma of a diagnosis is still so great, accompany the two stories. The package was illustrated with work by a local artist with schizophrenia, and ran as a special, ad-free section in the Sunday paper in November. Seidman’s account brought a poignant and intimate dimension to the topic, humanizing those with mental illness.

Many advocates consider rights for people with disabilities as the next frontier for civil rights. Stories on the subject sometimes bear a striking resemblance to coverage of women and minorities from only a few decades ago. “It really is not so different from ‘first woman’ stories,” says Kristin Gilger, director of the NCDJ and an associate dean at Arizona State University’s Walter Cronkite School of Journalism and Mass Communication. “For several decades, there were always newspaper articles about the first woman to do this and to do that. Just like with women and minority groups, it takes time for journalism to mainstream it into their coverage.”

The NCDJ administers the Katherine Schneider Journalism Award for Excellence in Reporting on Disability (<http://ncdj.org/contest/>), and Gilger cites some recent winners as representative of the way coverage is changing. Ryan Gabrielson of California Watch won in 2013 for “Broken Shield” (<http://californiawatch.org/broken-shield>), his series of stories about the Office of Protective Services, a California police force designed to protect developmentally disabled patients, and its failure to investigate the horrific abuse of patients, even when they died under mysterious circumstances. Despite federal audits, investigations by disability-rights groups, lawsuits, and thousands of pages of case files and government data showing facility caregivers and other staff choking, hitting, and sexually assaulting patients, hundreds of abuse cases went unprosecuted. Gabrielson’s 18-month investigation led to greater protections for the patients.

ProPublica won in 2015 for a story by Heather Vogell about a boy with autism whose hands were broken when he was restrained by educators and about the broader use of restraint on hundreds of thousands of other schoolchildren every year. The article, “Violent and Legal: The Shocking Ways School Kids are Being Pinned Down, Isolated Against Their Will” (<https://www.propublica.org/article/schools-restraints-seclusions>), detailed the common practice of educators to isolate and fetter uncooperative—and often, disabled—children, sometimes with handcuffs, bungee cords, and even duct tape.

The New York Times’s Barry was honored with the 2014 award for “The ‘Boys’ in the Bunkhouse.” After the story was published in March of that year, Barry decided to spend the rest of the year reporting on the disabled community. It wasn’t difficult to find untold, or incompletely-told, stories. For one, he focused on the marriage of a couple (<http://www.nytimes.com/2014/10/05/us/a-couple-gaining-independence-and-finding-a-bond.html>) who are both disabled and met in a sheltered workshop, where people with intellectual disabilities work in isolation at repetitive jobs for very low pay. Barry took this contentious issue and brought out the most human of elements: a happy couple in love, a bride and groom on their wedding day, and their joy at finding a life partner. He relates the smallest details, such as picking up balloons for the wedding party that don’t fit into the car and a nervous bride fretting over shoes that hurt.



Friends and family take pictures of Lori Sousa and Peter Maxmean, newlyweds who met at a sheltered workshop where they performed repetitive jobs Angel Franco/The New York Times/Redux

“The best thing news organizations can do to improve their coverage is to hire people with disabilities.”

—Mike Porath, founder of The Mighty

One simple way to improve coverage would be to train and hire more journalists with disabilities. “I think the issues stem from ignorance, not intent,” says The Mighty’s Porath. “The best thing news organizations can do to improve their coverage is to hire people with disabilities. There are a lot of great efforts to diversify newsrooms, but too often those initiatives are focused on gender and race alone. The best newsrooms will have people from all walks of life, including those with disabilities. All these life experiences and perspectives make newsrooms stronger.”

Journalism and Disability

Obstacles and Opportunities for Journalists with Disabilities

by Michelle Hackman

Making News Websites Accessible to All

by Michael Fitzgerald

That’s certainly the case for Chicago’s ABC7, where, for more than two decades, disability issues have been covered as a beat rather than an occasional side story. The station hired Karen Meyer, a broadcast journalist who has been deaf since birth, in 1991; for 23 years, Meyer’s regular on-air reports addressed everything from issues about wheelchair accessible playgrounds to protests in D.C. demonstrating against the fact that there were no statues of President Franklin D. Roosevelt in his wheelchair.

Having reporters on a disability beat remains rare, but ABC7 has remained committed to Meyer’s legacy of pioneering disability coverage, even after [she retired in 2014](http://abc7chicago.com/careers/abc7-eyewitness-news-reporter-karen-meyer-to-sign-off/294437/). The station appointed anchor Hosea Sanders and special projects producer Sylvia L. Jones to the disabilities beat after Meyer left, and the station broadcasts special reports on a disability issue each week.

“Sometimes reporters—as a reflection of society in general—will write about the poor, or people with a disability, or people with some kind of challenge, with a hint of condescension,” The New York Times’s Barry says. “You have to clear your head of prejudices.”

With reporting by Eryn M. Carlson

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