Routledge Research in Disability and Media Studies

DISABLED PEOPLE TRANSFORMING MEDIA CULTURE FOR A MORE INCLUSIVE WORLD

Beth A. Haller

"A vital love letter to disability media that doesn't just consider the limits of disability representation but gazes fondly at future possibilities. Engaging directly with disabled media creators, and backed up with important historical context, Haller offers a deep exploration into why new media platforms can offer exciting opportunities for mass audiences to hear different disability stories."

Jeff Preston, Ph.D., *Associate Professor, Disability Studies, King's University College, Western University*

"This book is truly a tour de force, combining theoretical and empirical research to map a broad and diverse spectrum of disability and media. Haller's skill to synthesise historical, social, cultural, political and economic layers of disability media creation and representation is unprecedented. The reading experience is enriched by each chapter focusing on a different media genre and deploying a different theoretical approach. Its interdisciplinary poise thus benefits a variety of disciplines, such as disability studies, media studies, anthropology and media practice-led research. Most importantly, the writing is engaging and accessible, embodying the same kind of inclusivity its content advocates for."

Catalin Brylla, Ph.D., *Principal Lecturer in Film and Television, Bournemouth University*

"With her decades of experience writing about disability issues as a journalist, in addition to her academic career in communication studies, Beth Haller is the preeminent scholar and chronicler of disabled people's uses of mass, print, and digital media – as creators, consumers, and critics – for their social, cultural, and political advancement. This book adeptly combines up-to-date examples with fresh takes on communication theory to offer readers unexpected insights into the past, present, and future of disability representation on-screen and online."

Meryl Alper, Ph.D., *Associate Professor of Communication Studies, Northeastern University*

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Disabled People Transforming Media Culture for a More Inclusive World

This book tells the stories of disabled people who have been influential in creating modern mass media.

Through the voices of key disabled media makers and collaborators, the author highlights the ways in which their contributions are changing society's understanding of disability and shaping mass media and culture. Spanning a range of media formats – television/streaming productions, performances, podcasts, TED Talks, films, reality TV, graphic novels, and social media channels – the book illustrates how disabled people are confronting the marginalization they have faced in mass media for decades. Modern disabled media creators are leveraging new media platforms to recognize the lived experiences of disability and their authentic place in media culture.

This innovative and thought-provoking volume will be an important read for scholars, disability advocates, and students of Disability Studies, Mass Communication/Media Studies, as well as mass media production faculty, disabled people, and their allies.

Beth A. Haller, Ph.D., has been researching mass media content about the disability community since the early 1990s. She developed some of the first university courses in the U.S. and Canada focused on disability in the media, for undergraduate and graduate Disability Studies programs at Towson University in Maryland, the City University of New York (CUNY), York University in Toronto, Canada, and the University of Texas-Arlington. Haller is co-editor of the 2020 *Routledge Companion to Disability and Media* (with Gerard Goggin of the University of Sydney and Katie Ellis of Curtin University, Australia). She is currently co-founder/co-director of the international nonprofit organization, the Global Alliance for Disability in Media and Entertainment. She is a retired Professor Emerita in the Mass Communication department at Towson University. She identifies as a neurodiverse person with multiple disabilities/chronic illnesses.

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For all the disabled, chronically ill, or Deaf media creators worldwide, what you are doing today *will* make the future accessible

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Introduction

My journey into disability media studies

My life has been informed by disability since childhood, but I didn't understand that until I found Disability Studies in 1991 at my first Society for Disability Studies (SDS)[1] meeting outside of Washington, D.C. Combining my interest and background in all kinds of mass media with my discovery of a vibrant Disability Studies academic community set me on my life's work, and thus this book about disabled people creating media and transforming culture across the world. When I attended my first SDS meeting, I was a master's student at the University of Maryland-College Park (UMCP) getting a degree in science communication. Before going back to graduate school, I had been a print newspaper journalist in Texas, Illinois, and New Mexico. As a journalist, I covered the health beat at two newspapers and that also got me thinking about the stories of disabled people I covered as part of that news beat in the 1980s. This book also discusses the bookended pandemics that have informed my media life. I covered the growing AIDS crisis in both Texas and Illinois in the late 1980s, when a hospice in Amarillo, Texas, kept their dying patients with AIDS a secret, and in Southern Illinois, when a man with AIDS broadly smiled at me in 1988 because I was willing to shake his hand. As I am writing this in February of 2023, the world is still dealing with the Covid-19 pandemic, according to the World Health Organization,[2] as am I, who continues to be one of the few Americans masking indoors in 2023.[3] Millions of people worldwide have died from Covid-19 complications or now have the new chronic illness, Long Covid.[4]

Being a health journalist and having a mother trained as a registered nurse gave me a deeper understanding of my own health conditions throughout my life. As a child, disabled people were always near, such as when I looked at my parents' 1960 wedding photos in which my mother's childhood best friend, Shirley Sue Smith, who was physically disabled from childhood polio in the late 1930s, stood smiling with the other bridesmaids. I can now reflect as well on the many family members and friends, including myself, who live with nonvisible disabilities/chronic illnesses. Many of these family and friends were negotiating disabilities and chronic illnesses, such as mental

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illness, intellectual disabilities, hearing disabilities, traumatic brain injuries, dwarfism, and cancer diagnoses, long before there were effective treatments, medications, or most importantly, understanding. Some of my own nonvisible disabilities were apparent in childhood, severe respiratory allergies and chronic ear infections that continued into adulthood. Other chronic illnesses grew worse as I aged, and I added related conditions or new ones all together. By the time I was in my early 30s, I had been diagnosed with food allergies in addition to respiratory allergies, adult-onset asthma (although my doctors think I had childhood asthma that no one understood because I have coughing asthma, not wheezing asthma), and a bladder condition called interstitial cystitis that is typically related to allergies. In my 50s, my first colonoscopy revealed that I was at high risk for colon cancer, which my father had been diagnosed with in 2016 and died of 2017. I had 5.5 inches of my colon removed to prevent colon cancer in 2017. An endoscopy at that same time showed I have esophagitis, an inflammation of the esophagus. In 2021, I was diagnosed with nerve damage (neuropathy) in both my feet and in 2023 a diagnosis of erythromelalgia in my feet means I have to avoid warm weather and walking too far. Writing Chapter 7 about media creators with nonvisible disabilities/chronic illnesses influenced me greatly because although I knew all their stories, I felt empowered by reading and writing about other people with nonvisible disabilities in-depth.

My brain is also neurodiverse. In addition to having anxiety since I was a child, I have sensory-processing sensitivity, both physically and emotionally, which is referred to as being a Highly Sensitive Person (HSP).[5] However, being an HSP as a child was not understood in the 1960s and 1970s when I was growing up,[6] and I am an only child who had a quiet environment with stable parents who rarely forced me into social activities, because my favorite pastimes were being at home reading, watching television, or being outside playing with one or two friends in an unstructured way. My hearing sensitivity was confirmed in 2011 when hearing tests revealed that I had better than 100% hearing at age 50. My ear, nose, and throat doctor said he had never had a patient at my age with my level excellent hearing because human hearing naturally degrades as we age. But I had inadvertently saved my hearing, too, by avoiding loud places throughout my life, preferring reading or walking through quiet nature. A graphic-novel memoir that I discuss in Chapter 5 had a profound impact on me. French writer Julie Dachez's *Invisible Differences* (2020)[7] tells the story of her autism diagnosis as an adult in France, which has outdated beliefs about autism that it has only begun to question in the last few years.[8] The abrasiveness of the neurotypical world on those of us whose brains are sensitive to sounds, smells, textures, and even conversations, became clear. Her memoir serves as a guide on how to reframe disability in one's own mind. Near the end of the book, the autistic main character Marguerite, becomes Wonder Woman flying through the air with text that says, "Concretely speaking, the challenges she faces remain the same, but her perception of them has changed: Not only has she learned to know and love herself, but she has also developed critical opinions on the way difference is pathologized."[9]

I believe being an HSP also shaped my career as a journalist and then an academic because becoming a writer gave me much control over who I talked to, where I went, and what I wrote. I began exploring journalism at age nine when I produced a neighborhood newsletter with a manual typewriter and print set that had been my father's. I was active on my high school newspaper and wrote my first disability story there, about a classmate's dwarfism due to growth hormone deficiency and the hormone treatments she decided to undertake.

I was writing about disability in my professional journalism career in the 1980s, too, with stories about the newly identified post-polio syndrome,[10] Down syndrome,[11] cystic fibrosis, mental illness, new treatments for heart disease, Medicaid, and the death of an early heart-lung transplant recipient.[12] I make no claims that I understood disability in a social model context yet,[13] but I can proudly say that I did interview disabled people for my stories whenever possible. One memorable person I profiled was Debbie Chandler in Amarillo, Texas, who has mosaic Down syndrome, and wrote a book about her life in 1986 and was looking for a publisher. She is a lifelong learner who loved to read and told me, "I always said I wanted to be a writer."[14] The Texas Department of Mental Health and Mental Retardation saw my article and reprinted it in its *Impact* publication that same year.[15] On a 2020 podcast episode, The Story Key, Chandler discusses her switch to writing poetry.[16] Two of her poems are in *A Room of Golden Shells: 100 Works by Artists and Writers with Down Syndrome*,[17] published by Woodbine House publishers in 2013.

My access to information in the newsrooms where I worked trained me early how to do deep research and led me to Disability Studies and to the many disabled Americans writing about disability rights in the pre-Internet era. Because I was a graduate student at UMCP, I was able to get a summer internship as a copy editor at *The Baltimore Sun,* and one day I happened to see a feature story about *The Disability Rag*[18] on *The Associated Press* wire service and decided to subscribe. In one of the first issues that arrived, I noticed a classified ad for a Disability Studies conference that was nearby in Rockville, Maryland. Through my many years at SDS conferences, I got to know disabled writers and editors who were fueling disability rights activism in the 1990s and beyond at places like *The Disability Rag* (founded in 1980), *Mainstream* (founded in 1975), and *Mouth* (founded in 1990).[19] Publications like *The Disability Rag* were a kind of "civil rights journal" for Americans with disabilities who were coalescing as a movement. "*The Rag* [was] about empowerment, not getting by. It's about validating real lives, and nothing [was] too sacred to be spared *The Rag*'s scrutiny."[20]

The late disabled writer Douglas Lathrop explains that these rights-based publications were a response to the persistent negative stereotypes in mainstream media of people with disabilities as inspirational or courageous. "In light of this persistent reliance on oppressive stereotypes, the disability press fills the void," Lathrop said.[21] Lucy Gwin, the editor of *Mouth*, explained: "Nobody [in the nondisabled media] is going to cover the disability-rights movement, so we're just going to have to cover it our own damn selves."[22]

Deaf president now

Because I arrived at the University of Maryland in 1989, one year after the Deaf President Now protests at Gallaudet University[23] in Washington, D.C., the world's only university for Deaf people, I became interested in the Deaf community. For a long-form feature writing course at UMCP, I profiled a Deaf Gallaudet student from Montreal, Canada, and discovered the oppression she felt within her hearing family. In my research and theory courses in my master's program, I began looking for research about the news media representation of Deaf people or disabled people. I found little. My master's thesis adviser, the late Katherine C. McAdams,[24] would become a dear friend and mentor and conducted research about the representation of race and gender in the news and encouraged my interest in writing a thesis on how the news media represented the Deaf community, before, during, and after the 1988 Deaf President Now movement.[25] I made contact with Gallaudet University sociology professor Yerker Andersson, who helped start Deaf Studies there, and he agreed to be on my thesis committee. I audited his sociology course at Gallaudet[26] and immersed myself in readings from Deaf Studies on my road to Disability Studies. A Deaf man who came to the U.S. from his native Sweden in 1955 to attend Gallaudet University, Andersson was a forward thinker who understood that the world must embrace Deaf people as a culture, not a medical diagnosis. As a longtime president of the World Federation of the Deaf, he advocated for countries to protect the rights of their Deaf citizens and recognize official sign languages.[27]

University of Maryland journalism history professor Maurine Beasley[28] sparked my interest in media history, and I found a rich journalism history within the American Deaf community. Deaf Americans have been transforming U.S. media culture since the mid-1800s when the first newspaper at a school for Deaf children in the United States began. These schools ended up empowering several generations of Deaf people because each one had its own printing press so Deaf boys could be taught the printing trade. I conducted research on these Deaf school newspapers, The Little Papers, and discovered that they were "a significant journalistic and cultural tool... Soon most deaf schools had their own newspapers published by their print shop. At one time, 50 periodicals were being published by deaf schools."[29] The school newspapers set the path for a vibrant group of periodicals that would serve the U.S. Deaf community for the next 100 years. Known as the "Silent Press," these non-school publications gave the community news from a deaf perspective. Like the exclusion many other U.S. minority groups felt, the mainstream news media did not cover the issues of the Deaf community.[30]

But many Deaf men worked as printers for U.S. newspapers throughout the 20th century so they were part of the mainstream news media as well. U.S. Deaf literature scholar Pamela Kincheloe says,

> Deaf people have always been on the forefront of new communication technologies, and the nineteenth century was no different; by the late 1800s, just about every deaf school in the country had made the switch from hand presses to professional-grade Linotype machines and cylinder presses. They also had well-trained printing departments that could handle all aspects of the process.[31]

She explains that the hands of Deaf workers helped create the texts and images for a generation of American publications.

> It is clear even from this very brief history of the production of The Little Papers, that, for almost one hundred years, a very large proportion of deaf labor was vitally connected to the physical creation and production of texts. Deaf hands were intimately familiar with the handling of paper, the composition of type, with the creation of and making of photoengravings, with the inking of forms, with the continuous, rolling production and reproduction of images and words. Because of the hands of deaf writers, illustrators, and printers, Deaf images and words were shared on a national scale. The labor, the production of the hand, the hand of 'silent workers,' resulted in reams of text—millions of words and images, in English, a language not entirely their own—a language with which, ironically, they had an ongoing, fraught relationship.[32]

Culturally, the Deaf community helped transform American print media for many decades.

My journalism history research also led me to another important figure in American Deaf media history, 19th-century Deaf journalist Laura Redden Searing. Laura Catherine Redden began writing professionally in the 1850s, right after completing her studies at the Missouri School for the Deaf. She became deaf in 1851 due to spinal meningitis, and her writing abilities were encouraged when she enrolled at the school for the deaf in 1855. Because she had a keen sense of observation honed by her hearing loss, she was perfectly poised to embrace the way American journalism was shifting to be an activity for writers to attend events and write about what they witnessed.[33] She wrote first for the *St. Louis Presbyterian* and then the *St. Louis Republican,* and by 1861, she was sitting in the press gallery in Washington, D.C. and covering the U.S. Civil War for St. Louis newspapers. In 1860, she decided to write under the byline Howard Glyndon; presumably, to avoid the sexism she might face as one of the few female journalists in the United States.[34]

A Union loyalist, she accompanied General Ulysses Grant to the front lines during the U.S. Civil War. After the war ended, Redden went to Europe to study the French, German, Italian, and Spanish languages. She spent much of the next three years in Italy, writing stories for *The New York Times*, the *New York Sun*, the *Missouri Republican*, and various magazines.[35] She became a writer for the *New York Evening Mail* and a freelancer upon her return to the United States. Through her extensive travel in both Europe and the U.S. in the 1860–1870s, Redden built a career writing about the places she saw and the people she met, everyone from Louis Napoleon in France to abolitionist clergyman Henry Ward Beecher to Slocum Howland, the New York Quaker conductor on the Underground Railroad who led enslaved Black Americans to freedom. Redden authored hundreds of articles during the journalism part of her career to about 1876.[36] She had a successful career as a poet after that and raised her daughter as a single mother. She is an unknown figure to most American journalism historians, but this Deaf woman was a pivotal figure in the changing journalism practices in the late 19th century.[37] This book highlights the modern version of Deaf or disabled people like Redden, who contribute to their contemporary media culture but do not receive the deserved recognition for their places in media history.

Disabled writers before the internet

In post-World War II America, disabled publishers, editors, and writers began trumpeting the need for disability rights and transforming media culture. Soldiers who had been disabled in war were audiences of some early publications like *Paraplegia News*, begun by disabled veterans in 1946. Its founders said the magazine was a "medium for the exchange of ideas in helping each other."[38] Many disability publications followed this same philosophy of trying to help other disabled people. For example, *Future Reflections,* a quarterly U.S. National Federation of the Blind (NFB) publication begun in 1981, is a platform for blind adults to address the parents of blind children so those children can have a better future. As the president of NFB said in 1981, *Future Reflections* "is a reaching out by the blind of this generation to offer help and encouragement (through parents) to the blind of the next generation."[39]

Polio survivors started several publications by and for that specific disability community as well. One of the most important figures of U.S. polio publications was Gini Laurie, who although she never had polio herself, lost three of her siblings to the virus in the early 20th century. Laurie began volunteering in a polio ward in 1949 and in 1958 became the editor of a newsletter for the Toomey Pavilion, a contagious ward in Cleveland, Ohio. That newsletter became a place where polio survivors could exchange information, even internationally: it "featured letters from polio survivors from all over the world with a focus on people with disabilities writing for other people with disabilities."[40] By 1970, that newsletter had become the *Rehabilitation Gazette*, which served people with all types of disabilities. "*The Gazette* has always been written by people who are themselves disabled. They talk about getting jobs, going to school, traveling the world, staying healthy, asserting their right to be treated with dignity. They talk about surviving."[41] In 1987, the twice-yearly *Gazette* reached an audience of 30,000–50,000 in 87 countries and was translated into five languages.[42] Another publication from polio survivor Ray Cheever was *Accent on Living* (it started as *Polio Living*), which began in 1956. He saw the need for an information source for disabled people after it took much searching for him to find a wheelchair. Cheever said in 1986 that it is "a magazine about people who happen to have a disability but yet have managed to become successful. It speaks of success by example."[43]

With my background in journalism, I became a bridge between disabled writers and editors and the field of Disability Studies, and I gathered many close friends from the disabled writer community as well. Writers with disabling conditions have always been around but only a few have been open about disability. William Stothers, a wheelchair user from polio, served as editor of the cross-disability magazine, *Mainstream*, from 1984 until 1998, when it closed. His wife Cyndi Jones, also a polio survivor, was the publisher of *Mainstream*, which was based in San Diego, Calif. But for the first six years of his work on *Mainstream*, Stothers also worked at the San Diego city newspaper, *The Union Tribune*, as an editor. He was one of the few wheelchair users working for a traditional city newspaper. Stothers said, in the 1980s and before, people who worked in journalism hid their disabilities if they could and identified as nondisabled. Stothers said in 1995

> At *The Union-Tribune* I counted around 25 people who had disabilities, but probably no more than three or four of them would identify themselves as disabled. These were people with visual problems, with hearing problems, with mobility problems of varying degrees of severity–but they didn't think of themselves as being disabled, and they certainly didn't identify with a movement.[44]

But in the days before the internet, the United States had many print publications and broadcast shows devoted to disability. The late Charlie Winston, a retired communication professor who was blind, published *America's Tel-ability Media* for several years in the 1990s, which was a 127-page directory of magazines, newspapers, newsletters, television, radio, and newspaper columnists who focused on disability.[45]

After *Mainstream* magazine had to be closed because of lack of advertising dollars, Jones and Stothers applied for and received a federal grant from the National Institute on Disability and Rehabilitation Research to disseminate independent living research, which they used to start the Center for an Accessible Society for that purpose.[46] Their goal was to use the traditional news media to get information about independent living research out to the general public, which obviously includes disabled people. Jones said in 1999 that many disabled people did not want to identify as disabled or be seen with a disability publication, so she thought getting disability information into the general news media was important. Jones explained:

> The truth is people with disabilities still need information, and I think that we're going to do a good job. We felt this thing about how important it is for us to get the message out to people on disability rights. People who are disabled don't even comprehend what that is. They're not going to pick up *Mainstream* or they're not going to pick up *New Mobility*. They're not going to touch a magazine about disability; they're not going to claim their disability. But they still need that information. Maybe by disseminating information through the mass media we're going to be able to actually enlarge the movement and let people know that they do have rights.[47]

I provided content analysis research for the Center about the news media's coverage of disability issues, in both traditional news media and in disability publications.[48]

In the pre-Internet years, most writers who identified as disabled wrote for disability publications, as well covering disability topics as freelancers for publications for nondisabled people. A good example is my longtime friend Kathi Wolfe,[49] a writer with low vision, who wrote for multiple disability publications like *Mainstream* magazine, as well as freelancing for *The Progressive*, *The Washington Post*, and Maturity News Service. As an out lesbian, she has written about the intersection of disability and LGBTQ+ issues for the D.C.-based LGBTQ+ publication, *The Washington Blade*, for many years. Wolfe has published several books of poetry[50] and continues to freelance for the legacy news media, as in her 2023 essay for *The New York Times* about how she watches and enjoys movies as a person with limited vision.[51] Wolfe, who was born in 1952, said she was discouraged from being a writer since her childhood in New Jersey when teachers told her: "Blind girls can't write."[52] But blind girls *can* write, as Wolfe did, and as deafblind icon Helen Keller proved during much of the 20th century, which I showed in my 2015 edited collection of Keller's magazine and newspaper writings.[53] In addition to writing 12 books, Keller wrote articles for newspaper and magazines such as *Good Housekeeping*, *Ladies Home Journal*, and *The New York Times*. In the early 1930s, she also wrote a little-known monthly magazine column for *Home* magazine, a women's magazine only available for purchase at Woolworth's stores.[54]

Popular culture highlights disabled people

As someone who loves television and was born in 1961, I remember many of the first glimpses of actually disabled people appearing on American TV. I don't remember being particularly inspired by seeing a disabled actor, but I had more of a budding journalist response – that it was good to see accuracy in a television show when a disabled person played a disabled character. Disabled writer Ben Mattlin says in his excellent 2022 book, *Disability Pride*, that his mother used popular culture representations to show him possibilities for life as a wheelchair user.[55] She told him about disabled Irish writer Christy Brown and that his favorite game show host Bill Cullen (*Name That Tune*, *The Price Is Right*) had a not-seen-on-camera limp from polio.[56] She played the record of "At the Drop of a Hat," featuring the British duo, singer, lyricist, and comedian Michael Flanders, a wheelchair user due to polio, and composer and comedian Donald Swann.[57] In Great Britain, Flanders has the distinction of being one of the earliest physically disabled performers regularly seen on television in the 1950s. His musical revue show with Swann was a hit in Britain, the U.S., and Canada. In fact, Walter Kerr, in *The New York Times* in 1966, said: "Flanders … skates about the stage as though his wheelchair were a swan boat in the process of making figure eights along the road to Valhalla."[58] Flanders had a career as a radio and TV broadcaster as well and appeared on numerous TV game shows and television specials from 1957 until his death in 1975. Because he was so famous for "At the Drop of a Hat," audiences knew he was a wheelchair user. His biographer and archivist, Leon Berger, summed it up this way: "I think the fact you've got Michael Flanders in a wheelchair sitting up on stage is pretty pioneering. I can't think of a single example, certainly not in the UK, of a public figure who's been disabled."[59] The exposure of TV and theater audiences to a beloved star who used a wheelchair potentially transformed some attitudes about who was "allowed on television." British writer and TV critic Chris Davies, who has a disability, said television was his "window to the world" and seeing Flanders flew in the face of his notion that "television didn't show 'people like me.'"[60]

For me, seeing actors like disabled actor/comedian Geri Jewell, who has cerebral palsy (CP), on *Facts of Life* (1979–1988), stroke survivor Ellen Corby on *The Waltons* (1972–1981), and Chris Burke, an actor with Down syndrome, on *Life Goes On* (1989–1993) confirmed to me as a young person that disabled performers were the equal of nondisabled actors. In Chapter 1, I detail Jewell's tumultuous journey on American television until she found a show creator, David Milch of *Deadwood* (2004–2006), who was willing to collaborate with her in shaping an authentic disabled character.

Chris Burke's role as the main character on *Life Goes On* was pivotal and positively influenced future generations of actors with disabilities, as well as many U.S. families that included a member with Down syndrome. These families had never seen the similar experiences of their family depicted before. Burke had been interested in acting and performing after growing up in a loving family who supported his interests. Burke saw Jason Kingsley, a child actor with Down syndrome, on *The Fall Guy* in 1984 (he was also a regular on *Sesame Street* appearing in 55 episodes during the 1970s) and that truly ignited his passion for acting.[61] "Back in those days, a parent looked at the disability and didn't see the ability," Burke said. "*Life Goes On* showed that people with a disability can be included. Just give them a chance and let them learn. That's what the show was trying to teach."[62]

Actors with Down syndrome also got a boost when Blair Williamson, an actor with Down syndrome, and his mother Gail Williamson entered the picture. Hollywood agent Gail Williamson, who I interviewed for this book, became educated about TV characters with Down syndrome even before Blair's 1979 birth when her doctor asked her to spend more time relaxing and to watch a TV soap opera for an hour each day. That soap opera featured a baby with Down syndrome being born, Williamson said, although she did not know she was about to have a child with Down syndrome. Like Chris Burke, the first actor she saw with Down syndrome was Jason Kingsley, the child actor with Down syndrome who appeared on *The Fall Guy*.[63]

Williamson and Perl Kingsley, the mother of Jason Kingsley, became the catalysts for more disabled actors on television. Perl Kingsley wrote for New York-based *Sesame Street* from 1970 to 2015 and was able to "showcase many adults and children with disabilities on *Sesame Street*, including her son Jason, singer Andrea Bocelli, Israeli violinist Itzhak Perlman, actor Christopher Reeve, among other high-profile people with disabilities."[64]

Gail Williamson in Los Angeles saw Blair develop performing skills early on; his teacher suggested acting classes for him when he was five, she said. She saw his potential when he took a bow after completing a puzzle. By age ten, Blair was shooting his first TV commercial, a Proctor & Gamble ad for the Special Olympics. It aired in the first episode of the second season of *Life Goes On* in 1990. These experiences with Blair's acting career led Gail Williamson first to work as a contractor for the Media Access Office, which promoted access and employment of people with disabilities in the entertainment industry. After that, she worked at the Down Syndrome Society of Los Angeles and founded a group in 2003 to create a pipeline for performers with Down syndrome into the entertainment industry, Down Syndrome in Arts & Media. In 2012, she joined KMR Talent as an agent representing performers with a variety of disabilities.[65] Blair Williamson continues his career as an actor in short films and as a guest star on a number of TV shows.[66] Her work as a Hollywood agent for disabled performers is featured in Chapter 1.

Ellen Corby of *The Waltons* played the beloved grandmother character when she had a stroke in 1976 and returned to the show in 1978 with a significant speech disability and a mild mobility impairment. Corby had already won three Emmys playing Esther Walton and was on a show that did not shy away from tough topics as it was set in rural Virginia during the Great Depression. Canadian disability and accessibility consultant Haley Gienow-McConnell's 2019 doctoral dissertation on disability representation in *The Waltons* illustrated through her interviews of production team members and the show's actors, how their own perspectives on disability shaped the show's disability themes. She says,

> The life experiences, professional constraints, material and cultural circumstances, and personal views of those involved in making *The Waltons* influenced the series depictions of disability, suggesting that when it comes to disability and popular media, what we see is not a straightforward transmission of ideas and beliefs about disability. Rather, these representations of disability are an amalgam of circumstances and influences.[67]

Earl Hamner, the creator of *The Waltons* and upon whose life the book and TV show were based, said Ellen Corby made the decision to return to the show herself, even with limited speech. He added that he hoped the show that included Corby's disability would be a role model for viewers

> I like to think *The Waltons* has affirmed things that have made people feel good about themselves or helped them live their lives somehow. It may have helped overcome adversity in the Ellen Corby case where she had her stroke dramatically there on the air. The knowledge that she has struggled to attain even the limited speech that she has, that personal example of the actress in this case, must be encouraging to some people who've had a stroke or have some disability to overcome.[68]

A *TV Guide* writer quoted Hamner in 1977, saying "she will be portrayed as exactly what she is: a stroke victim fighting hard to recover her speech."[69] Gienow-McConnell's says that Hamner's positive attitude toward Corby's return to the show that would include disabilities illustrated that *The Waltons* would become a disability friendly production. Gienow-McConnell explains, "Suddenly it was conceivable that a person with a disability could appear on television, and unabashedly perform within the embodied experience of their disability."[70]

With all this authentic physical, sensory, and intellectual disability representation coming to the fore in the 1970s and 1980s, one might think that the momentum was there for it to continue. Williamson, who has been promoting the employment of disabled actors since the 1980s, believes the reason disabled characters began to dwindle was the AIDS crisis. She said, organizations that supported employing disabled people in the entertainment industry began shifting their funding to AIDS organizations.[71] (AIDS shifted from terminal illness to a chronic condition in 1996 when a combination of medications helped the immune systems of people who were HIV positive recover).[72]

In Chapter 7, this book discusses the arrival of characters with HIV/AIDS in American TV and film.[73] It happened on *Life Goes On*. Actor Chad Lowe joined the cast in 1991 as the HIV-positive character Jesse McKenna. Jesse and Corky's sister Becca date, and the storylines dealt with the stigma of being HIV-positive and the problems that arise when romantic couples are positive and negative. Lowe won an Emmy in 1993 for his portrayal of Jesse. At that time, AIDS had no cure, so *Life Goes On* in a flashback scene in the fourth season, reveals that Jesse died of AIDS.[74]

Williamson says that although there was less funding for disability advocacy in the entertainment industry during the early years of the AIDS crisis, advocacy did not stop. The Deaf community still had "dining room advocacy" opportunities where people gathered and discussed in ASL what they should be doing, she said. But she says the broader cross-disability community did not get that until social media arrived, creating a situation in which the disability community could ask other disabled people to highlight things important to the community. And Williamson says, the entertainment industry was slow to include disability in its diversity initiatives. After 1992, there was a vice president for diversity at every Hollywood studio, but people with disabilities were not included, she explained. Disabled performers were not included in the annual CBS diversity showcase until Williamson reached out to actor Melissa Gilbert (*Little House on the Prairie,*1974–1983), who was SAG-AFTRA president from 2001 to 2005, and who called the head of the CBS Corporation and told him that disabled performers should be included. Williamson says, media executives take notice when nondisabled actors advocate on behalf of disabled actors because they are seen as equal peers.[75]

Disabled people MUST be involved in mass media at all levels so representation improves, especially so disabled children and teens can see possibilities for their own futures, and the American disability community has literally been saying this for decades. In 1987, the CBS network in the U.S. hired disabled actor Jim Byrnes, who is a double-leg amputee, as a main character on the Emmy-winning undercover police drama, *Wiseguy* (1987–1990).[76] Byrnes gave the same reason for disabled actors to be hired for roles on TV that we hear today – giving aspirational goals to other disabled people, especially children. "I can't help but believe that when a kid who's lost a leg sees someone in a wheelchair on TV, he doesn't feel quite so alone," Byrnes said.[77] In 2019, disabled filmmaker and media consultant Dom Evans says that "better visibility of disabled people – truthful, meaningful portrayals of the lives they actually live" helps disabled young people, who many times face bullying or even familial abuse, look to a future world as a positive place for them.[78] And adults with disabilities/chronic illnesses need to feel represented in media in the here and now. In January 2020, I helped organize a screening of German journalist and filmmaker Karina Sturm's[79] documentary, *We Are Visible*,[80] at Chapman University in Southern California. The documentary details Sturm's journey with Ehlers-Danlos Syndrome (EDS) and others internationally, as they try to find medical experts and emotional support for a more recently discovered chronic illness.[81] About 100 people, most with EDS and their family members, drove several hours to attend the screening.[82] Their gratitude about finally having a film that showed their experiences was palpable. They wanted the film to be shown widely, especially in medical schools and nursing schools, so the world knows they are not "faking" their disabilities.[83]

A disability studies framework about disabled media creators

This book highlights the voices of disabled people creating mass media around the world. Its content is based on in-person and Zoom interviews, reading dozens of Deaf or disabled people's memoirs, videos, TED Talks, and podcasts featuring disabled creators discussing their work, and even reality television episodes in which disabled cast members discuss their lives. Their stories of innovative media-making and performance are analyzed through a Disability Studies and/or media studies lens.

Chapter 1 looks at how disabled producers, directors, writers, and actors who have power in the production of entertainment media content are disrupting ableist stereotypes long represented in television and film. For too long, nondisabled people created disability representation, and their disabled characters are the embodiment of Disability Studies scholars David Mitchell and Sharon Snyder's concept of narrative prosthesis.[84] In the narrative prosthesis framework, disabled characters are placed into the storylines of literature, film, and television to bolster themes of tragedy, villainy, inspiration, cure, etc. British DS scholar Colin Barnes says these ableist stereotypes that "medicalise, patronise, criminalise and de-humanise disabled people abound in books, films, on television… They are fundamental to the discrimination and exploitation which disabled people encounter daily, and contribute significantly to their systematic exclusion from mainstream community life."[85] The chapter underscores the work of actor/comedian Geri Jewell's work on *Deadwood*, the influence of Academy Award-winning Deaf actor (and now director) Marlee Matlin, the 2021 film *CODA* that stars multiple Deaf actors, the many clients of Hollywood agent Gail Williamson, who represents disabled performers, the inclusive film production and training organization in Australia, Bus Stop Films, which is committed to collaborative sets filled with disabled people as the actors, writers, and production crew, and the many initiatives in Great Britain and the United States that put disabled people in charge of their representation (Easterseals Disability Film Challenge, Channel 4 Engage and Enable program in the UK, the disability committee of the U.S. Screen Actors Guild, and Zeno Mountain Farm's film program).

Chapter 2 focuses on reality TV and TED Talks that star disabled people. It argues that by giving a platform to disabled people, reality TV shows and TED Talks can educate viewers about disability in an authentic and personal way, because in these formats, disabled people are speaking directly to their audience. The chapter discusses the parasocial contact hypothesis[86] about television audiences and posits that reality TV performances by disabled cast members could lessen prejudice against disabled people because the audiences form a parasocial relationship with disabled cast members. The idea that parasocial interactions and parasocial relationships in which TV audiences develop a feeling that they “know” the performers on programs has been around since the 1950s[87] but only more recently has it been investigated as a way to reduce prejudice toward marginalized groups appearing on television.[88] TED Talks from disabled people are purposefully connected to disabled reality TV stars in this chapter using the discourse analysis research of Italian English scholar Giuseppina Scotto di Carlo. Her analysis of TED speakers discovered how significant the personal connections of the speakers to their topics are for audiences.[89] Disabled people around the world are connecting to millions of viewers through their TED Talks about their lives and experiences. This chapter is based on my interviews with *Born This Way* reality star Rachel Osterbach and German disability rights leader Raul Krauthausen, who has done four TED Talks. The chapter also discusses the reality shows *The Specials* in the UK, *Love on the Spectrum* and *Employable Me* in Australia, the newest iteration of *Little People Big World* that focuses on Zach Roloff and his family, *Push Girls* and its critique by several DS scholars, and Deaf producer/actor/model Nyle DiMarco’s work as a winning cast member on *America’s Next Top Model* and *Dancing with the Stars* and as a producer of Netflix’s *Deaf U*. These are disabled people who are “cripping” reality TV to use American DS scholar Carrie Sandahl’s term.[90]

Chapter 3 delves into the world of disabled podcasters, vloggers, Instagram influencers, and TikTokers. Applying research done about podcasters from the U.S. Black community,[91] this chapter shows that this online audio and video from disabled people is a form of public pedagogy, a concept from Canadian global television scholar Henry Giroux.[92] Giroux explains that democracies are enhanced when citizens use new forms of online media that are not part of the capitalistic media structures that shut out many voices. Giroux says new online media platforms are “creating non-commodified public spheres and forums that could provide the conditions for critical education”[93] of a society’s citizens. Even if disabled people don’t think of themselves as educating with their online video and audio, audiences are learning about the lived experience of disability through podcasts, YouTube, Instagram, and TikTok. The chapter features an interview with Canadian podcaster Andrew Gurza, who is a gay man with CP who wants the world to know that disabled people are sexual beings. The chapter features the behind-the-scenes story of the 100-episode Disability Visibility podcast from U.S. disabled activist/writer/media maker Alice Wong, which ran from 2017 to January 2021.[94] Wong’s podcast amplified the many voices of the disability community, and she says the power of disability podcasts is that they can live online forever. Since its beginning, YouTube has provided a way for millions of disabled people to tell their stories and connect with others. Shane Burcaw, who has SMA, and his nondisabled wife, Hannah Aylward Burcaw, say they want their YouTube channel, called Squirmy and Grubs, to help change the media narrative about disability for the better. In an apt example of public pedagogy, they explicitly state that they hope to educate their viewers:

"In everything that we do, our goal is to normalize the disability experience. We strive to educate while we entertain."[95] Across the world from Kenya to Indonesia to Australia, disabled people are sharing videos on a variety of platforms, which empowers them and other disabled people. This chapter also mentions the controversy with Chinese video platform, TikTok, shadowbanning[96] disabled people who TikTok does not believe are "attractive" enough. German journalists at Netzpolitik documented these discriminatory content moderation practices in 2019, and they were featured in the 2022 U.S. documentary, *TikTok. Boom.*[97] With content moderation reminiscent of U.S. "ugly" laws,[98] TikTok hides content from some disabled people from its For You feed. Finally, the chapter reflects on the ableist standards about the vocal differences of disabled people that contributed to their absence in legacy media. U.S. media and cultural studies scholar Bill Kirkpatrick says the money-making orientation of traditional news media led to the invisibility of disabled voices and bodies in radio, in particular. Listeners believed they only wanted to hear a certain kind of "voice" on the radio. Kirkpatrick says the business orientation of the broadcast news industry reinforced "the ideology of 'compulsory able-bodiedness' and the rejection of disability identities."[99]

Chapter 4 looks at disabled performers who create entertainment programming for the Web and streaming television. The chapter uses the work of three disabled performers to illustrate the Affirmative Model of Disability.[100] This model of disability confronts the marginalization of disabled people trying to work in the entertainment television and film industry for decades. With new media platforms that have fewer gatekeepers, modern disabled creators are finding value and empowerment exploring their disability identity in self-created content. Through innovative web series, comedy performances, Netflix shows, and more, these disabled creators affirm their lived experiences of disability and its authentic place in media culture. The importance of the Affirmative Model of Disability cannot be understated because it is reacting to the personal tragedy model of disability that is so embedded in media and cultural content worldwide. Coming from the disability arts movement in Great Britain, the Affirmative Model of Disability adds to the Social Model of Disability, it doesn't replace it. The Affirmative Model allows disabled media creators "affirmative, empowering choices of identity and a politics of difference."[101] British disability and inclusion scholars John Swain and Sally French, who created the Affirmative Model of Disability, say that through the creation of media and art, disabled artists challenge the cultural barriers and societal oppression that shape disabled people's identities.[102] The chapter focuses on three primary disabled creators, Teal Sherer, Ryan O'Connell, and Hannah Gadsby. American disabled actress Teal Sherer, who is a wheelchair user, faced down inaccessible Hollywood when she tried to break into the entertainment industry in 2005 and after. Her connection with a successful YouTube series, *The Guild*, gave her the idea to make her own trials and tribulations as a disabled actor into a YouTube series. The result is two seasons of the short-form Web series, *My Gimpy Life* (2012, 2014).[103]

Sherer is a pioneer who was leveraging the relatively new media platform of YouTube for entertainment content (YouTube began in 2005), which now has 500 hours of new video content uploaded every minute.[104] *My Gimpy Life* gave Sherer a creative outlet both to affirm her disability identity and to connect with the larger disability community, who could watch the show for free as long as they have access to YouTube. Autistic queer comedian Hannah Gadsby's journey from Tasmania, Australia, to international fame came from her authentic stories told through her Netflix comedy specials, *Nanette* (2018) and *Douglas* (2020). Gadsby's out and proud performance of autism in *Douglas* relates to the way the Affirmative Model of Disability empowers disabled artists to no longer keep their disabilities a secret and to visibly embrace their disability identity to counter an assimilationist society.[105] Gadsby uses her neurodiverse brain to give audiences perceptive comedy and thus affirms the legitimacy of the autistic community's authentic autistic experiences through her own. In a Netflix short-form series, *Special* (2019–2021), American writer/actor Ryan O'Connell explores his story of being a gay writer with mild CP, who was closeted about his disability. Because their content appears on the streaming platform Netflix, O'Connell, like Gadsby, had much creative control. O'Connell says, "creatively, they've [Netflix] been dream partners and [let me] make exactly the show that I wanted to make," he said. "I'd rather make two seasons of television that are exactly my vision rather than four seasons where I felt like I was making creative compromises."[106] This chapter also explores the place of streaming platforms like Netflix in what film and media culture researcher Jason Mittell calls Complex TV Storytelling that focuses on serialization that engages viewers in such a way that they have to keep watching to get the full story, which is unlike the TV structure for dramas and sitcoms in which each episode has a story that wraps up at the end.[107] This Complex TV Storytelling style fits well with disability narratives that are many times nuanced and multifaceted and need to be told over multiple episodes.

Chapter 5 combines art, comics, graphic-novel memoirs, and music to explore how disabled people use these to create what Disability Studies scholars like Margaret Price[108] and G. Thomas Couser call counter-discourse that challenges "the dominant cultural tropes of 'invalidity.'"[109] These disabled artists, musicians, and media creators are fighting against their erasure in cultural narratives. Indian health humanities scholars Sathyaraj Venkatesan and Sweetha Saji call the graphic-illness memoirs they studied (Ellen Forney's *Marbles*, 2012, and Rachel Lindsay's *Rx: A Graphic Memoir*, 2018) forms of "productive resistance" that reconfigure representations of disabilities through both words and images.[110] In addition to Forney's *Marbles*, this chapter discusses other graphic novels and graphic-novel memoirs by disabled people: Cece Bell's *El Deafo* (2014) that became an AppleTV+ three-part animated series for children in 2022, French writer and blogger Julie Dachez's *Invisible Differences* about her autism diagnosis as an adult (*La différence invisible* published in French in 2016 and in English in 2020), and the disability story of Barbara Gordon (Batgirl/Oracle) who became a paraplegic wheelchair user in the 1988 Batman comic[111] with her true disability story being told in 2020 by the Dutch autistic YA writer Marieke Nijkamp when she wrote *The Oracle Code,*[112] (a YA graphic novel in collaboration with illustrator Manuel Preitano). This chapter also illustrates the natural convergence of graphic-novel memoirs and music through the work of Krip Hop Nation's Leroy Moore, who was interviewed for this chapter. Moore says he had an awakening about the power of graphic-novel memoirs when he read the 2007 graphic-novel memoir disabled rapper MF Grimm (Percy Carey), *Sentences: The Life of MF Grimm*, published by DC comics.[113] It showed him the intersecting power of comics and hip-hop music, he says. Moore created his own graphic novel in 2019, in which he includes some of his own real-life story as a disabled Black teen watching rap music unfold in 1980s New York City but the graphic novel focuses on a superhero story of a young, modern-day, wheelchair-using Black woman, Roxanne, who "brings disability Justice into Hip-Hop."[114] The chapter also discusses research by Australian music scholar Anthea Skinner[115] about the Krip Hop Nation-inspired animated music video by Kounterclockwise for their song, *Whip* (2013).[116] Skinner says the music video illustrates disabled solidarity and resistance. Finally, the chapter examines the many instances that disabled musicians, past and present, have pushed a counter-discourse in their lyrics and performances to resist the discrimination and ableism they have experienced.

Chapter 6 focuses on documentaries about or by disabled people. Because documentaries are a significant place of representation of the disability community, the chapter includes some of the powerful documentaries by nondisabled directors that illustrate the ableist society and barriers disabled people face. These documentaries about the disability community fit with disabled artist Riva Lehrer's concept of "mirror hunger," [117] which she defines as "the longing for a reflection one can claim as one's own." [118] Lehrer says disabled people discovering their community through art and media can be transformational to them: "One of the greatest problems we have is that people don't want to identify as disabled. Disability community fosters our identity, encourages our cultural development and reflects the complexities of our experiences."[119] The chapter recounts the changes in video camera technology and later digital video tools that allowed everyone, including disabled people, to get behind the camera and shoot their own documentaries. An event in 1981 also shifted interest in documentary filmmaking about the disability experience, the International Year of Disabled Persons (IYDP).[120] Barbara Kolucki, an international expert in inclusive communication who edited the *International Disability Video Catalogue*,[121] said that new worldwide awareness of disability issues helped shift the video content about disability into more empowering and less framed within the medical model or a pity or "Supercrip" approach.[122] This year-long event led to a more collaborative approach between nondisabled directors and the disabled people in the documentaries. Disability Studies scholars David Mitchell and Sharon Snyder's pivotal disability culture documentary, *Vital Signs* (1995), illustrated a process of storytelling they call their "communal documentary."[123] Mitchell and Snyder, who do research about disability documentaries, say documentary films about disability create a kind of global map, guiding audiences and disabled people themselves to a more inclusive future.[124] Disabled documentary filmmakers say their disabilities enhance their ability to do the collaborative work that making a film requires.[125] *Invalid Corps* (2019) [126] by documentary director Day Al-Mohamed, who is blind, says "Disability, at its heart, is about adapting to the environment, collaborating with others and accommodating each other to be successful."[127] The chapter details the new organization for disabled documentary creators, FWD-Doc, Documentary Filmmakers With Disabilities, which tries "to increase the visibility of, support for, and direct access to opportunities, networks, and employment for D/deaf and disabled filmmakers."[128]

Chapter 7 is about part of the disability community that is most often forgotten in media representations, even though they are the largest part of the disability community worldwide – people with nonvisible disabilities/chronic illnesses. In addition to their disabling conditions, these disabled people have to make decisions about disclosing their disabilities in the face of disbelief, mocking, and sometimes even violence. U.S. gender and Disability Studies scholar Ellen Samuels, who identifies as disabled, says many people with nonvisible disabilities/chronic illnesses "may feel that our choice is between passing and performing the dominant culture's stereotypes of disability."[129] Sometimes people with nonvisible disabilities/chronic illnesses are not accepted by people with apparent disabilities. This chapter relies on the research of U.S. Disability Studies scholar Susan G. Cumings, who analyses how people with nonvisible disabilities are using a variety of social media and online platforms to show their lives and experiences with conditions that are not readily apparent.[130] Cumings' analysis illustrates how disabled creators in social media/online spaces challenge ableism and foster community for others. Cumings explains that

> Media tools at the disposal of disabled persons in charge of their own representation facilitate creative multimodal storytelling that challenges all of us to be better receivers, interpreters, and carriers of each other's stories, stories that are at once multiple and singular, fragmentary and whole.[131]

The chapter applies Cumings ideas to the work of American disabled YouTuber/artist/social media activist Annie Segarra, who identifies as a queer, Latinx person with multiple nonvisible disabilities. Segarra is a significant voice for this community, creating much video content on their Annie Elainey YouTube channel like "Ambulatory wheelchair users exist" and the hashtags, #TheFutureIsAccessible. The chapter highlights the Peacock streaming channel reality show, *Born for Business* (2021), with two of its four cast members being women with nonvisible disabilities: Qiana Allen of Chicago, who has lupus and runs a fashion business for plus-sized women with a retail store and online shopping site, and Lexi Zanghi of Long Island, New York, who has an anxiety disorder and runs her online shopping fashion brand.[132] The reality television show gives unparalleled visibility to people with nonvisible disabilities, as well as showing how disabled people support each other in times of trouble (the Covid-19 pandemic began in the middle of shooting *Born for Business*). Finally, Chapter 7 considers the musical dramedy American television show, *Crazy Ex-Girlfriend* (2015–2019),[133] which drew so much attention from academia that a 2021 book of essays, *Perspectives on Crazy Ex-Girlfriend, Nuanced Post-Network Television,*[134] critiqued The CW Network show in terms of its feminism and representations of gender identity and mental health. Disability studies and medical rhetoric scholar Caitlin E. Ray writes that the show is an example of a crip narrative, with its the nonlinear plot, the cripped perspectives of the main character Rebecca Bunch (an attorney who is eventually diagnosed with borderline personality disorder, BPD), the musical numbers shifting time, and the rejection of traditional negative stereotypes of mental illness.[135] Created by American singer/actor/comedian/writer Rachel Bloom, who has been open about her diagnoses of anxiety and depression,[136] the show drew praise from people with BPD and other mental health disabilities. Bloom says her own mental health has improved through being open and honest about it and telling the story of mental illness in her work. She says, “The idea that there should be any stigma around treatment or being depressed or anxious [that] labels you with a scarlet letter is nonsense, and openness and normalizing it helps everyone.”[137] *Crazy Ex-Girlfriend* gives a powerful voice to a character with a nonvisible and heavily stigmatized disability, and most importantly, Ray says, “her cripped perspective is valued and honoured.”[138]

This book has been a true joy to write and gives me hope for the future of disabled media creators. In my research process, I often found many more examples from disabled media creators than I could ever use. I would look for information on media created by one disabled person and find ten more equally as rich and interesting. I told *Disability Pride* author Ben Mattlin about my optimism about the younger generation of disabled people leveraging everything new forms of media and technology have to offer which he quoted in his book:

> They definitely understand disability discrimination but they are fighting against it through words on social media, videos, writing books, etc. They also understand that getting better and more authentic disability representation in popular culture and media can help change society’s attitudes toward disability. They may not know much about the history of disability discrimination but their activism is using modern tools to do their advocacy work and these tools fit with these times.[139]

Now the challenge is to get disabled media creators into positions of power in all aspects of mass media industries so they can continue transforming media culture in all societies.

Notes

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1 Collaborating on set to disrupt narrative prosthesis

Disabled characters in television and film have long been shaped by nondisabled producers, directors, writers, and actors, sometimes even when an actor with the lived experience of disability was on set. For many decades, if a disabled character was in a TV episode or film, that character was used as an embodiment of Mitchell and Snyder's concept of narrative prosthesis,[1] in which disabled characters inform central storylines with themes of tragedy, villainy, inspiration, cure, etc. Disability Studies (DS) scholars have long known that disabling stereotypes "medicalise, patronise, criminalise and de-humanise disabled people abound in books, films, on television… They are fundamental to the discrimination and exploitation which disabled people encounter daily, and contribute significantly to their systematic exclusion from mainstream community life," British DS scholar Colin Barnes says.[2] Disability has been used for these ableist metaphors since Shakespeare's time, but disabled writers and performers began to see their negative impact in the late 20th century as disability rights began to be embraced in countries like Great Britain and the United States. Polio survivor Victoria Ann Lewis,[3] who became a performer and later theatre professor, founded Other Voices at Los Angeles's Mark Taper Forum in the 1980s, in which disabled theatre artists wrote plays and created performances that challenged these negative tropes. She says, "disabled characters shaped by the old cautionary and sentimental models of representation have filled the stage for generations, from the stigmatized Oedipus and Richard III to Tiny Tim, the special child who manifests innocence and goodness in the world."[4] To change this, Lewis explained in 2001:

> Theatres need to recognize disability as part of the diversity agenda. And our casting practices need to reflect those of other minority communities, in which every effort is made to provide employment for qualified actors with disabilities. We need plays that reflect this experience, not only so that [disabled playwright] John Belluso and [blind playwright/actor] Lynn Manning can make a living, but so that we as a country can embrace our bodies as they age, as they change, as we need each other. We really have a great story to tell at this crossroads in the American experience.[5]

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Disabled Australian writer and comedian Alistair Baldwin says that TV writers are so wedded to disability as a prop for the nondisabled protagonist that it creates a structure that excludes disabled actors:

> Even for supporting characters, narrative prosthesis strongly preferences depictions of disability where ability is the norm, i.e. acquired disability.
>
> When disability becomes a narratively 'useful' way of externally illustrating a protagonist's internal arc, it creates a dynamic where disabled characters often cannot be protagonists themselves.
>
> Writers that identify the symbolic utility of disability position disabled people as object to an abled person's subject, and this becomes its own self-perpetuating pattern…[6]

Baldwin adds that nondisabled screenwriters must unlearn the negative stereotypes and clichés they use in television and film. Disability and psychology researcher Richard Amm's work on how to portray disability in film without reinforcing prejudice found that disability as a metaphor is embedded into the education of future screenwriters through seminal textbooks.[7] *The Definitive Guide to Screenwriting* by Syd Field[8] specifically says to make a character disabled "to imply moral failure."[9]

This chapter argues that the only way to disrupt the inauthentic ableist metaphors in film and television will come from members of the disability community being involved in all aspects of television and film productions. Disabled people will need to be on all sets to combat the ableism in Hollywood, in particular: "Disabled people will continue to be marginalized if they are not given the same opportunities to work in Hollywood. And, play meaningful roles and not further entrench stereotypes,"[10] says blogger Lisa Lightner. People who embrace a disabled identity know about the interdependence and collaboration needed for most aspects of life, and that is essential in the creation of television and film. Disabled novelist A.H. Reame says interdependence should be lauded as a "transformational force" because it allows many creative disabled people to produce their artistic endeavors.[11] A spirit of collaboration within disabled/nondisabled production teams also builds inclusion. Australian inclusive filmmaker Genevieve Clay-Smith says when film sets include people with disabilities in every aspect of production, "it is a wonderful collaborative way to break open our industry; bring people in; develop people's skills and affect culture positively."[12] This chapter highlights the many disabled people who are beginning to replace ableist narratives in film and television with authentic stories from the disability community.

Deadwood

Disabled actor Geri Jewell, who was the first person with cerebral palsy (CP) to have a recurring role on American television, had been on Hollywood television production sets since being cast on *The Facts of Life* (1979–1988) in

1980, but she never had much input into how her disabled character was presented until she was hired for a role on the HBO television show *Deadwood* (2004–2006). In her 2011 memoir, *I'm Walking as Straight as I Can*, Jewell writes openly and honestly about her naïveté and gullibility when she began working in professional acting jobs. She even says she was about age 12 in her knowledge of the world, when she stepped onto *The Facts of Life* set at age 24.[13] It is clear that her exclusionary life as a disabled child and teen led to much of her ignorance about how the world works. Jewell, who is also hard of hearing, had been in various therapies for her CP since she was a toddler and was in segregated educational settings until high school, one of which was so far away from her home that she spent a six-hour round trip on a school bus to get to that program. That gullibility led to a tumultuous time on the set of *The Facts of Life* because she was being exploited and manipulated by a manager who stole her money and gave her bad professional advice. He was arrested for embezzlement and securities fraud. She was eventually fired from *The Facts of Life*, became addicted to sleeping pills, dealt with pain from aging with CP, had a toxic marriage to Richard Pimentel, whose life as a man deafened in the Vietnam War is chronicled in the film *Music Within* (2007), and came out as a lesbian. She struggled financially for many of those years, making a living as a stand-up comedian and public speaker. In fact, she was living with her sister because she could not afford rent and was receiving government disability assistance when she got the job on *Deadwood*.

Jewell says most productions saw her as a way to insert disability into a storyline, but *Deadwood*'s creator David Milch took a collaborative approach, asking her to help shape the character, Jewel, who cleaned the saloon/brothel in the show. Jewell read about Deadwood, South Dakota, in its formative gold rush years, about Western legends like Calamity Jane, Wild Bill Hickock, and Buffalo Bill Cody, as well as about the history of CP, which didn't have a name until 1921. She fashioned a backstory for the character, imagining the life of someone with CP in the post-Civil War era.[14] Milch told Jewell he "loved her writing… and was very impressed with my own vision of the character."[15] After a meeting with Milch, he noticed she was dragging her left foot and she lied and said it was connected to her CP, instead of the actual story, which was that she fell and broke it the day before. When she got her script, Milch wrote in that limp for the Jewel character. She didn't want the character to continue to limp after her real injury was healed so she came up with a creative solution and pitched it to Milch:

> I told him that I thought Doc Cochran (played by Brad Dourif) should build Jewel a leg brace like the kind some soldiers wore after being injured in the Civil War. I thought it would be a powerful storyline, and then I wouldn't have to drag the leg anymore.[16]

Milch loved it and incorporated the leg brace storyline into the last two episodes of Season 1, with an empowering scene in the finale episode with Doc

Cochran and Jewel, now more stable on her feet with the leg brace, having a dance at the Gem Saloon.

In another scene, Jewel offers to bring Swearengen and his guest tea, and he quizzes her about why she visited the doctor, because his spies have already revealed her visit. She quips to him, 'I'm knocked up.' That shuts him up for a second, then he grabs the teapot and insults her ability to pour it without spilling. It's a unique moment for a TV show — treating a person with a disability equal to anyone else, even if that means treating her badly. And her retort to him even allows her character to have a sexual identity. In the real Deadwood, 90 percent of the women were prostitutes.[17] Jewel doesn't appear to work as a prostitute, but viewers can be sure that if a patron requested her, Swearengen would offer her up quickly.[18]

Jewell remained a member of the *Deadwood* cast when HBO wrapped up the series some years later with an HBO feature-length film in 2019. Milch, who is a recovering heroin addict, completed the film four years after receiving a diagnosis of dementia. In 2022, he did an interview with *The New York Times* and discussed his more recent Alzheimer's diagnosis.

It should be noted that Jewell was discovered doing stand-up comedy[19] by someone who could be called the first powerful nondisabled ally in Hollywood, long-time TV creator Norman Lear (*All in the Family, Good Times, Maude, The Facts of Life, Diff'rent Strokes, One Day at a Time, The Jeffersons* and many others). His socially conscience shows had feminist and anti-racist tropes long before they were considered topics by anyone else with power in Hollywood. When interviewed in 2020 by disabled entertainment writer Kristen Lopez, Lear, who was born in 1922, said he wanted to reflect the authentic society he knew, having grown up with disabled people in his Connecticut neighborhood: "It just made sense to include disabled characters and, more importantly, disabled actors, to emphasize the world we lived in."[20] In addition to discovering Geri Jewell and casting her on *Facts of Life*, he put disabled child actor, Melanie Watson, on *Diff'rent Strokes*. Watson said that although she bristled at some of the inspirational storylines using her on the show, she still applauds Lear for his inclusive casting. "I'm proud of Norman for going against the norm and doing something," she adds.[21] Disabled TV writer Allen Rucker said one of Lear's shows, *Maude* (1972–1978), spoke an important truth (and often a theme in disability representation) when the deaf actor/singer Nanette Fabray played a stroke survivor in a 1977 episode[22] – that nondisabled people are fearful of disabled people because they perceive them as tragic figures. Fabray's character, who has slurred speech because of the stroke, asks Maude, "I scare you, don't I?" Maude replies: "You scare the hell out of me."[23] Two years after that episode, Lear helped create the Media Access Awards in California to give accolades to those who highlight disability in an empowering way in their TV and film content.[24]

Disabled writers began to get jobs in Hollywood as well. *Deadwood* tapped disabled playwright John Belluso (1969–2006) as a writer for the series in 2004. Although he only wrote one episode, "The Trial of Jack McCall," it was used as an example of good television writing from a disability perspective for a Dramatists Guild of America meeting in 2006 at HBO headquarters in New York City. Writers, actors, directors, and filmmakers gathered at HBO headquarters in New York to discuss how to write about disability to create authentic portrayals. At the meeting, disability theatre professor and the editor of the book *Beyond Victims and Villains: Contemporary Plays by Disabled Playwrights* Victoria Ann Lewis paid tribute to John Belluso, who had died two months before the meeting. Lewis said that Belluso plays, which all featured disabled main characters, rejected the tragedy model of disability:

> The one story John was dead set against is: the triumph of the exceptional individual over a personal tragedy. This was not John's story - because this story denied the economic, social, and historical conditions of disabled people across time…John's stories are filled with the texture of a life lived with a disability.[25]

Belluso wrote from his experiences as a disabled man growing up in the burgeoning U.S. disability rights of the 1970s and beyond. He saw the disability rights movement as allowing him to have a life in theatre arts. As a wheelchair user, he helped transition theatrical spaces to accessible for disabled actors. At the Los Angeles's Mark Taper Forum, Lewis founded the Other Voices Project, which gave theatre training to disabled people and focused on "creating texts to challenge the depiction of disability in drama and the mass media."[26] When the Taper Forum mounted the Belluso play, "The Body of Bourne," about the U.S. disabled intellectual and World War I pacifist Randolph Bourne, the space needed to become accessible.[27]

> In 2001, the entire backstage of the Taper had to be renovated for the premiere of his play 'The Body of Bourne.' A ramp and accessible, ground floor dressing rooms and bathrooms were installed, causing [Pulitzer Prize-winning playwright] Tony Kushner to comment: 'How many playwrights physically transform the theatre they're working in?'[28]

Belluso continued to work in television in the last two years of his life, as the story editor of *Ghost Whisperer* (2005–2010), for which he also wrote an episode, as well as writing two episodes for *Eyes* (2005–2007).

HBO has long been a supporter of filmmakers with authentic images of people with disabilities. It gave some financial support to filmmakers for the independent documentary films *King Gimp* (1999 Academy Award winner) and *Educating Peter* (1992 Academy Award winner), both of which subsequently aired on HBO. But HBO, like most of the entertainment industry, falters when it doesn't have disabled people involved in its productions. Warner Bros. Discovery, which owns HBO,[29] faced backlash over the HBO Max film, *The Witches* (2020), in which Anne Hathaway's character appears to have the limb difference, ectrodactyly. Disability advocates with limb differences protested that she uses her disability to cement her status as a villainous character: "Having Anne Hathaway use her hands and feet as terrifying weapons throughout the movie's runtime is something that said community took umbrage with."[30] HBO could have avoided this ableist trope if people with limb differences were consulted.

Deaf actors in film and television

Deaf actors have a unique relationship with television and film because they can "pass" as nondisabled until they communicate. Any discussion of modern-day deaf actors must begin with Marlee Matlin, who became the first deaf person to win an Academy Award for her performance in *Children of a Lesser God* (1986). She is still the youngest person to win a Best Actress Award at the age of 21. In addition to being deaf, Matlin is a recovering drug and alcohol addict[31] who went to the Betty Ford Center to get sober within days of winning her Oscar.[32] Matlin had been acting since she was a child in Chicago and mentored by disabled actor Henry Winkler (*Happy Days*, *Barry*), who has severe dyslexia.

When she began her post-Oscar career, some in Hollywood thought she would never work again, believing that a deaf person playing a deaf person was not acting.[33] Matlin showed them they were wrong by appearing in more than a dozen films and starring or guest starring on more than 50 television shows. But even with all her success, it is only in recent years that she has been able to be a collaborative force on set.

Matlin's first starring role on television, *Reasonable Doubts* (1991–1993), went from enjoyable to unpleasant in its two seasons. The legal drama centered on the working relationship between an assistant district attorney (Matlin) and a police detective (Mark Harmon). As they shot the second season, Matlin says the focus became more on Harmon's character and that Harmon was having difficulty mastering so much dialogue that he was supposed to deliver in sign language. As a young actor in her 20s still new to television work, she said she was quickly pushed aside.

> The writers would come in and observe, but never really talk to me. I tried throwing a few ideas their way and got a few story lines added that brought in other Deaf actors for an episode or two. But there was no real collaboration.[34]

Even with a short-lived show, Matlin was nominated for an Emmy for Best Actress in a Drama Series.

Matlin explains the best collaboration between a Deaf actor and a film or television production comes from the writers who learn how to adjust for an actor using a visual language, not an auditory one. “It always starts with the script,” she says,

> And in *Children* there is almost no air – as I was signing, dialogue kept running, translating everything for audience but in a way that felt natural. It was written so that you are hearing Bill’s [William Hurt] character’s reactions as well as seeing them. Randa [Haines, the director] spent hours planning, adjusting shots in different ways, to catch the action between me and the other actors.[35]

Matlin says other TV creators/showrunners who knew how to write for a Deaf actor were Aaron Sorkin (*The West Wing*, which she starred in 2000–2006), Carol Leifer (her guest spot on *Seinfeld* 1993), Gary David Goldberg (her guest spot on *Spin City* 1993), and David Kelley (*Picket Fences*, which she starred on 1993–1996). She adds: “You can look at any of those episodes and they flow seamlessly; the dialogue between me and the other characters feels organic. As an actor, those are the qualities you are looking for.”[36]

Matlin has also selected roles that highlight the intersectional roles of Deaf or disabled people. She has been vocal supporter of LGBTQ+ rights and her brother is gay, so it added an interesting dimension to the lesbian drama, *The L Word*, when she joined the show on the premium cable network, Showtime, in 2007. She says she sees parallels between homophobia and discrimination against Deaf people.[37] In media coverage about her joining the show, she said:

> The discriminatory practices against the GLBT community parallel almost exactly those against deaf and hard of hearing individuals. Misunderstanding, stereotyping and discrimination – of these things which have happened to the GLBT have been routinely happening to deaf people for years.[38]

She played another role with an LGBT theme on *Picket Fences*, which included a scenario in which she carried a baby for her character’s brother and his partner.[39] Ransom and Haller studied Matlin’s character on *The L Word* who they call “a complex deaf character on TV” and explained:

> Too often deaf characters on TV are only in one episode and the plot revolves around some image of deafness as a deficiency. Whereas in *The L Word*, the Jodi character is on equal footing with the other characters and brings some aspects of Deaf culture into the show. She is in a romantic relationship with a hearing person, she is a famous artist, she is a friend and teacher and she interacts in the world using both sign language and spoken English. *The L Word* writers also show us that at least one of Jodi’s former partners was a Deaf woman who not only is frustrated that Jodi has moved on but implies she is resentful that she may be leaving the deaf community. And it is possible that by speaking

> so much in the role, Jodi is single handedly making hearing people more comfortable hearing deaf speech on TV.[40]

However, Matlin has been often criticized by the Deaf community for using multiple communication methods in her roles: American Sign Language (ASL), Signed English, and her voice. Her use of verbal speech may be a way to confront the taunts she received as a child for her deaf speech.[41] She has often faced backlash in the Deaf community when she speaks. When she used verbal speech to present the Best Actor Award during the Academy Awards in 1988, she was criticized.[42] Deaf Studies scholar Tom Humphries, who is deaf, disapproved of Matlin speaking: "She's choosing to focus on a stereotype that deaf people had tried to avoid, the whole idea that deaf people have to speak to be successful. That's offensive to many people, including me." When she was prepping for her starring role on *Reasonable Doubts*, she chose to use Signed English because she felt it was a more detailed way of communicating that an attorney would use.[43] She said her choice angered some in the Deaf community,[44] but her decision was defended by another of her mentors, the famed U.S. Deaf stage actor Bernard Bragg

> I wrote an article defending Marlee's choice. It was a very good and wise decision on her part. For the role of a lawyer, she needed to use specific and exact words. She proved herself to be a versatile actress by using the bona fide ASL as a Deaf mother in the recent TV movie *Sweet Nothing in My Ear* (2008). I think it is great that she has helped the general public see and appreciate the difference between the two.[45]

Her multiple communication methods are also a necessity in the continuing ableist, audist hearing world of Hollywood. Matlin lending her support to many projects from or starring members of the Deaf community over her 35+ year (and still going strong) has helped build some access and awareness in Hollywood. She had a supporting role in the Freeform teen drama *Switched at Birth* (2011–2017), which had a more inclusive production team and set. Its hearing showrunner Lizzy Weiss did research at a deaf high school in Los Angeles and saw quickly that the Deaf actors would need to use sign language:

> I learned so much that day and spoke to dozens of deaf teenagers about their lives and their experiences. And so, this is, of course, in the middle of writing the pilot, and I said to the network, you know, deaf kids wouldn't voice orally. We would have to have those scenes only in ASL, and no sound and they said, 'Great. Let's do it.' And frankly, we just kind of grew and grew from there.[46]

And although all the writers on the show were hearing, they all watched the documentary *Through Deaf Eyes* to learn more about the U.S. Deaf community. Writer Joy Gregory said, “That was like a very concentrated, opening of the eyes, getting a deep rich human understanding of the history and what’s at stake for the deaf community.”[47] Based on interviews and a visit to the *Switched at Birth* set, that better understanding of the Deaf community seemed to foster a more collaborative spirit on set. Gregory told a story about Deaf actor Sean Berdy’s notes on one of her scripts when she wanted to include a close-up of his hearing aid. Berdy emailed, “I hope you understand this is very sensitive to the deaf community. Please don’t do this so close-up.” The on-set Deaf consultant agreed with Berdy saying that to some in the Deaf community, a hearing aid is “a symbol of oppression” and they would be offended by the show highlighting it.[48]

Switched at Birth also highlighted issues that the U.S. Deaf community faces such as the closing of Deaf schools and their all-ASL instruction, the lack of knowledge about Deaf history of younger Deaf people, and the intersection of Deaf people who are BIPOC or LGBTQ. To illustrate one issue, the show had an all-ASL episode on the anniversary of the 1988 Deaf President Now protest that successfully got a Deaf president installed at the U.S. University for Deaf people, Gallaudet.[49] Matlin and other actors on the show would live tweet about Deaf issues while the show was airing thus educating the predominantly hearing audiences about them. Disability and media scholar Elizabeth Ellcessor explains how the added social media presence conveys a deeper understanding of Deaf issues

> The transmission of Deaf cultural and political concerns is furthered by the extension of *Switched at Birth* beyond the television screen. Actors, including Matlin, participate regularly in live Twitter events as the program airs. This enables Matlin to address viewers of an episode (connected via hashtag #SwitchedatBirth) by hailing them as potential activists. In one exchange, Matlin writes ‘Lack of interpreters on weekends, no videophones – inexcusable and it’s ILLEGAL but it HAPPENS to deaf ppl all the time! #SwitchedatBirth’ (2015). This takes a plot element of the show, and reframes it as a larger social issue.[50]

Popular shows like *Switched at Birth*[51] gave hearing audiences an appetite for more Deaf stories and opened up spaces for other Deaf-focused productions. *This Close* Deaf actors and showrunners Shoshannah Stern and Josh Feldman said they wanted to convey the variety of Deaf people’s experiences, because people have different levels of hearing loss, different backgrounds, and different ways they interact with the world. Feldman elaborated

> We also came up with some specific experiences that hearing people didn’t realize would be different for deaf people—like the hospital or camping in the woods. With Season One, we had to be a little bit more simple and not too heavy on the deaf stuff. Just in case you know, it would alienate people. We knew that wasn’t going to happen now for

> Season Two so, we believe the audience is more ready to delve into specific deaf-lived experiences.[52]

This Close was first developed as a short-form web series that premiered at the Sundance Film Festival in 2017. Then it became a series for the Sundance digital platform, Sundance Now. They received feedback about the web series at Sundance that helped them fashion the half-hour comedy once it moved to the Sundance cable channel. Feldman said, the fact that hearing people embraced the show gave them encouragement to take the series farther.[53] Stern and Feldman also took this opportunity to create an employment pipeline for Deaf people who want to work on a TV production: "We had 18 Deaf people working with us behind and in front of the camera and this season we're challenging ourselves to beat that," Stern said of Season 2 in 2019.[54]

In 2022, the film Best Picture Oscar win for *CODA*[55] solidified that Deaf-hearing collaboration on a major film production could become the norm. Once again Deaf actor Marlee Matlin was instrumental in making that collaboration happen by firmly stating that she would not participate in the film unless Deaf actors were hired to play Deaf characters:

> I said to [the producers], 'If you don't listen to me, and you don't respect me and my community, then I won't be in the film.' People think that, like with makeup or a costume, you can just put on being deaf or being disabled. It doesn't make sense, because there are so many deaf actors out there who can represent our community.[56]

CODA is about the teen hearing member of an all-Deaf family who wants to pursue singing but functions as the sign language interpreter for the family's fishing business. *CODA* is an English-language remake of Éric Lartigau's French film *La Famille Bélier* (2014), which cast hearing actors to play the Deaf family members. *CODA* director Sian Heder says that when she was trying to get the film made through a Hollywood studio, Lionsgate, it was not allowing her to cast Deaf actors

> This started as a studio film, and studios function with a financial model driven by stars and foreign box office. We were getting pressure that we needed to have stars. I was the only one pushing for three deaf actors but once Marlee was cast there were two of us and we said, 'You guys need to juggle the way you finance things to find a way.' Those were tricky conversations. Ultimately, it did not happen at the studio and happened independently.[57]

Producer Patrick Wachsberger was the former co-chairman of the Lionsgate Motion Picture Group and was already working with Heder on CODA; he was able to get the project out of Lionsgate so Deaf actors could be hired.[58]

Wachsberger says that the production's commitment to hiring Deaf actors never wavered, and he also would not have been involved if hearing actors were cast to "play deaf."[59]

But even with authentic casting, *CODA* had critics in the Deaf and CODA communities. They felt that the film reinforced negative themes about Deaf people, viewing the community through a hearing person's perspective and presenting the Deaf family as an "inconvenience" for its hearing member. "The ways deafness is presented as a burden to the hearing community perpetuates harmful assumptions about disability… and the film naturalizes false stereotypes: that being deaf means that you can't enjoy music or understand anyone else's enjoyment."[60] Even *The New York Times* took note of the Deaf community's criticism of *CODA*

> In interviews and on social media, some deaf people and children of deaf adults, known as CODAs, say they feel torn: While they hope this moment will lead to better recognition and open doors for more representation throughout Hollywood, they argue that the film views deaf people from a hearing perspective in its approach to interpreting for deaf people and to their relationship with music, among other issues. In some cases, this 'hearing gaze,' as some have called it, led to scenes that may resonate with hearing viewers but fall flat with deaf viewers or even upset them.[61]

Everyone applauds Deaf actors being cast, but Deaf writer and consultant Jenna Beacom says that fact can't overcome its harmful message:

> The movie is about, at its core, the terrible burden of deafness and the terrible burden of being born hearing to a deaf family. And the nice moments layered on top of that core are not enough to obscure it.[62]

Some actual CODA's, who are hearing members of the Deaf community, said the film is not authentic to their experiences because non-CODA actor (British actor Emilia Jones) plays the hearing teen. Australian artist and CODA Jodee Mundy OAM wrote a detailed Facebook post about the problem with that choice, saying no one in the cast or production team is a CODA. "They cast a person who didn't sign and still called the film CODA… why?!! This is unethical. This term is the intellectual and cultural property of codas. It's about identity in which the line has been crossed and disrespected."[63] Being a CODA is the core of Mundy's identity, which she has created a theatrical performance about.[64] She says:

> I'm a native signer who hears and has Deaf heart.
>
> Coda means I embody Deaf culture even though my ears hear.
>
> Coda means I am a heritage signer and a respectful of Deaf people as the custodians of signed languages.

> Coda means I sign like a Deaf person even though I'm not Deaf.
> Coda means I am a deep ally to both the Deaf and hearing communities
> Coda means to intersect the worlds of the Deaf and the hearing.
> Coda means to intersect both the signing and speaking worlds.
> Coda means to straddle inclusion and exclusion.
> Coda means to intersect ability and disability.
> Codas have been around since Deaf people had babies which is thousands of years.[65]

CODA the film gives the world a mixed structure of authentic Deaf actors but no authenticity of CODA lived experiences, with problematic themes that fall into the category of narrative prosthesis. U.S. Deaf Studies scholar Pamela Kincheloe argues that ASL now functions as a narrative prosthesis in the North American media because it is not signifying the actual language of the Deaf community. She says, "you can find ASL seemingly everywhere; it is being inserted more and more into the cultural mainstream, but is not appearing as a language. It is used, nine times out of ten, as a decorative ornament, a narrative prop."[66] Kincheloe adds,

> This trivialisation [of ASL] can in turn continue to reduce the lived experiences of deaf people to a sort of caricature, further reinforcing the negative representations of deaf people in America that are already in place, stereotypes that we have been trying to escape for over 200 years.[67]

The hearing world's devaluing of the language and culture of the American Deaf community could be seen even when it was giving back-handed praise to *CODA*, as when *Entertainment Weekly* expressed shock that what it called a "modestly scaled and relatively star-free drama" sold for a record-breaking $25 million at the Sundance Film Festival in January 2021. It called the premise of a hearing person in a Deaf family "sweet" and "tender-hearted,"[68] which smacks of an underlying inspiring theme that would resonate with hearing audiences.

But even with its flaws, *CODA* has led to more recognition in U.S. film and television for Deaf performers/writers/creatives. The *Wall Street Journal* reported in July 2022 that

> Major studios and celebrity producers are picking up projects that would have previously been dismissed, and filmmakers are placing deaf performers and creatives in high-profile roles. At the same time, children's shows and reality television have made greater efforts to showcase characters and participants who are deaf or hard of hearing. It's a major shift for an industry where deaf representation has been scarce.[69]

Troy Kotsur, who won the Best Supporting Actor Oscar for his role in *CODA*, believes the film resulted in hearing people getting over some of their fear about the communication and cultural differences of the Deaf community, saying that "people who have never experienced Deaf culture can perceive an irrevocable communication gap between deaf and hearing people."[70] He will star in a series for Disney+, based on the true story of a deaf high school football team in California; Marlee Matlin is executive producer of the series. Matlin has added director to her skills by directing an episode of the Fox series *Accused*. She is happy to have so much Deaf talent join her, saying "I had been doing it alone for a long time. With *CODA* now, suddenly it really hit the point home. People understand that there's more than just me."[71]

Deaf screenwriter, actress, and producer Shoshanna Stern of *This Close* has written for the show *Echo*, which stars Deaf actor Alaqua Cox. Stern will also write and star in the AMC Network's *Disquiet*, which is a drama-thriller. Deaf actor James Caverly returned to his role on Hulu's "Only Murders in the Building" in 2022 to be called the "conscience" of the murder mystery show that stars Steve Martin, Martin Short, and Selena Gomez. He said bringing his Deaf character Theo to life was a collaborative process on set. Caverly explained:

> 'Sadly, there are one too many creators who write disabled characters as two-dimensional: fixating on their disability without room for growth.' Theo is different in large part because Caverly helped create him. He had multiple conversations with Hoffman and director Cherien Dabis 'to figure out how to portray Theo authentically without feeling like a gimmick. Aside from the dialogue changes, we talked about how a Deaf person views the world,' describing Theo as 'a true collaborative effort' between the creators and myself to bring the character to life.[72]

Jevon Whetter, a deaf writer and actor, and his brother Del were tired of waiting for productions to include more Deaf stars/writers/directors so decided to produce their own film, *Flash Before the Bang*. It is about a state champion track team at an Oregon deaf high school that they both attended. The film is being co-produced by Matt Damon and Ben Affleck's Pearl Street Films.[73]

The American Black Deaf community's actors, producers, directors, and writers are finally making their way onto Hollywood sets. Lauren Ridloff, who is Mexican American and African American,[74] became the first Deaf superhero in the Marvel universe film, *Eternals* (2021).[75] Ridloff has a master's in education and worked as a New York City elementary school teacher before being cast in the Broadway revival of *Children of a Lesser God* in 2018, where she had been advising the director as a sign language coach.[76] She also starred in the last several seasons of the original AMC television show, *The Walking Dead*. Ridloff is set to executive produce and star in a Starz network romantic drama with her white hearing *Children of a Lesser God* co-star Joshua Jackson in a series created by African-American director Ava Duvernay.[77] To address the lack of opportunities for Black Deaf TV and film creators in the entertainment industry, award-winning Black Deaf filmmaker Jade Bryan created Deaf Talent® in 2012. Bryan says Deaf Talent is a social movement to "raise awareness for those who are Black and POC, including those with other intersectional identities, (LGBT+) who have been systematically boxed out of the Film and Television industry."[78]

With more Deaf producers, directors, writers, and performers involved, the storylines in future film and television will hopefully move away from the use of sign language and Deaf culture as a narrative prosthesis that trivializes the experiences of Deaf people.

Neurodiversity and intellectual disability fuel authenticity

Gail Williamson, the former Hollywood agent for disabled performers at KMR Talent in Los Angeles, says performing comes naturally to many people with intellectual or developmental disabilities because many have been directed by parents and caregivers since their diagnosis. Williamson's son, actor Blair Williamson who has Down syndrome, has been a guest star on television series since the 1990s (*ER, Scrubs, CSI, Ratched*),[79] and she began her career on Hollywood sets with Blair.[80] In that role, she saw the need for talent management for the many children with disabilities who wanted to pursue acting. U.S. laws enacted in the 1970s that required equal public education for all children, including those with intellectual disabilities, meant young people with intellectual disabilities could now pursue their dreams to work in the entertainment industry. Williamson said that knowing her son's interest in acting as a child, she felt there needed to be adult role models with Down syndrome in media. "That is the fire behind me," she says.

> It was to allow every child to turn on TV or watch a movie and see themselves – see themselves because they don't. I mean, we had the joy of [wheelchair user] Ali Stroker who got a Tony [in 2019] and her acceptance speech was, this is for all those kids. And here's this woman in a wheelchair taking Broadway by storm,

Williamson explains in an interview with Daisy Hampton.[81] Hampton is a New York City middle schooler who started a non-profit, Including You, at the beginning of the Covid-19 pandemic to provide technology and mentoring to students who, whether due to disabilities or income inequality, face educational barriers. Williamson says it is crucial that disabled children see disabled actors on screen:

> Everybody wants to see themselves represented onscreen. That's acceptance. The screen teaches us and we teach the screen. It goes both ways. But what you're doing, Daisy is teaching the screen. Think of the

> [Including You mentees] who may go on to be decision-makers, who may go on to be filmmakers, you know, they're going to have a whole different experience and they're going to portray their experience. And likewise, when we put it onscreen, other people go, 'I know that guy in my apartment building in a wheelchair, maybe I should go chat with him… maybe I should ask him out for a cup of coffee.'[82]

Williamson says the work of developing the talents of these young performers with Down syndrome in Southern California began in 1996 when actor Mary Rings, who also has a son with Down syndrome, created the Born to Act Players. Rings wanted performers like Blair Williamson and her son Casey, who has Down syndrome, to have access to acting classes.[83] The group continues to train actors with Down syndrome and those with other developmental disabilities like autism. *American Horror Story* actor Jamie Brewer, who has Down syndrome, joined the Born to Act Players when she moved from Texas to Southern California. Williamson said Brewer's first professional audition was for *American Horror Story*, where she has since starred in multiple seasons 2011–2018.[84] Brewer also became the first person with Down syndrome to star in an off-Broadway play, *Amy & the Orphans* in 2018,[85] and to model during New York Fashion Week in 2015.[86]

Williamson says that the performers with disabilities she represents made $3 million in 2019 (compared to the $50,000 her clients made in 2013). The casting of actors with disabilities has changed for the better in the last few years, moving from the narrative prosthesis[87] use of a disabled character who makes a narrative all about their disability within an ableist storyline to being a starring or supporting character who happens to have a disability. Williamson says that, "today, they [disabled characters] are just people and we're getting more and more of that."[88]

> At this point, [the Diversity Department] will get calls from casting directors saying, 'Of these three roles, I have the school counselor, the barista and, the attorney. Do you want to look at them [for clients with a disability]?' And we'll submit people. And the attorney may end up being in a wheelchair or a barista may end up, you know, having Down Syndrome or being on the Autism Spectrum. The counselor might end up even as an amputee or someone who's deaf.[89]

Autistic creators and actors are also finally having some power in the U.S. entertainment industry. Australian comedian/writer/actor Josh Thomas went to Hollywood after the success of his first TV show, *Please Like Me* (2013–2016) in Australia, which dealt with mental health, and developed *Everything's Gonna Be Okay* (2020–2021) for the U.S. Freeform network, which has the distinction of being the first American TV series to hire an autistic actor to star. Thomas, who was diagnosed as autistic while working on the show, says when he auditioned autistic actor Kayla Cromer, her performance was much more genuine[90] than the neurotypical actors:

> Neurotypical girls had read for Matilda, but, Thomas said, they all slipped into a 'sort of robot voice.' After meeting Kayla Cromer on the first day of auditions—and seeing her give a spirited, expressive performance—Thomas knew she was right for the role.[91]

One of the autism consultants on *Everything's Gonna Be Okay* helped Thomas find a doctor to get his autism diagnosed. All aspects of the show were vetted by Cromer, actress Lillian Carrier, who is also on the spectrum and played Drea, and the autism consultants, and as Thomas crafted each episode, he began to see his own connections to being autistic. Thomas committed to authenticity for his own character in the show, saying he wouldn't make Nicholas on the spectrum "unless I confirm that I'm actually autistic."[92]

Television productions are finally understanding that disabled mimicry,[93] a term coined by disabled director Dom Evans for when nondisabled actors play disabled, is especially egregious for autistic characters because the voice and behaviors of nondisabled actors playing autistic appear to be mocking people on the spectrum. Autistic stage actor Mickey Rowe says disabled mimicry "shuns actual disabled actors and other artists whose lived experiences are reflected in the narrative but who rarely get to be included in the creative and production process," adding that "we are the experts on our own lives."[94] Disabled mimicry causes many problems in media representation. In addition to propping up ableist narratives, it denies disabled people a voice; takes jobs away from disabled actors; gives no disabled performers the ability to serve as role models for actual disabled people; sends a message that disabled people are inferior actors; and probably the worst is that disabled mimicry spreads misinformation about disabilities to media audiences. Disabled entertainment writer Esme Mazzeo became so fed up with inauthentic representation that she began reaching out to the television productions that hired nondisabled actors to play disabled characters to inquire about its "discriminatory choice." One showrunner would not listen to Mazzeo's critique, claiming she didn't know "all of the facts" about the production. But, Mazzeo says, "the facts are that I'm a disabled woman who felt uncomfortable with the way my identity was being portrayed on TV."[95]

Other autistic actors are finally getting roles such as Vanessa Burghardt in *Cha Cha Real Smooth* (2022) and the Amazon Prime Video series *As We See It* (2022), which has three leads all on the autism spectrum, Rick Glassman as Jack, Sue Ann Pien as Violet, and Albert Rutecki as Harrison. But these projects received mixed reviews, with criticism that they stuck with neurotypical tropes about autism. A British education lecturer wrote that *As We See It* had many problematic scenarios that would be damaging to autistic people, like being forced to live in a noisy, crowded city, requiring an autistic person to make eye contact, and being dominated by a family member.[96] Autistic writer Claire Davidson says Burghardt has sparkle as an actor but was trapped in a shallow narrative in *Cha Cha Real Smooth*:

> The broader inclusion of autistic actors within the film and television industries is a net positive for the future of entertainment. Autistic talent is present everywhere, and allowing autistic actors to imbue their characters with our unique sense of joie de vivre makes these portrayals that much more compelling in representing the full bandwidth of our emotionality. However, even Vanessa Burghardt's promising young voice can't rectify the film's failure to create an autistic character whose needs are understood and accommodated.[97]

One short animated film stands out in its commitment to an authentic autistic person's portrayal, Pixar's *Loop* (2020). The film is about a neurotypical boy Marcus who is told by a summer camp counselor that he will canoe with Renee, who is a nonverbal autistic girl. They meander through the water and experience each other's perspectives a bit. It is the first film to feature a nonverbal autistic character whose sounds and behaviors are based on the mostly nonverbal autistic young woman, Madison Bandy, who portrayed her. To best accommodate Bandy, the production team decided to record her at her home, where she was most at ease.[98] The film also had consultants from the Autistic Self Advocacy Network (ASAN) about what did and didn't work in the film. Autistic Disney film fan Ethan Holloway says, "Renee as a character is what authentic autism representation should be, a character that does everything correctly, from the little gestures and noises we make to her obsession with a ringtone on her phone, which she finds comforting."[99] Autistic YouTuber and parent Willow explains some of the ways *Loop* breaks with traditional negative stereotypes of disability in film; for example, by not having nondisabled Marcus appear as a hero and not falling into the trap of inspiration porn.[100] One of Willow's commenters, Angel Gonterman, added how the film relates her lived experience with autism

> I'm autistic and while I'm not like the girl, there's one part that I relate to on such a personal level that I could never explain. The tunnel scene where she hears that loud noise and it's unbearable, it makes her panic, it hurts, and I cried because that's exactly how it feels! Whenever I describe my aversion to some noises, I have a hard time explaining what it feels like. That was a perfect explanation of what I go through.[101]

Gonterman's comment is a poignant example of why media must have authentic representations of disability because it allows disabled people to feel seen and it helps build understanding from nondisabled audiences.[102] The late U.S. disability rights pioneer Judith Heumann studied disability in media as a

Ford Foundation Fellow in 2018 and said as a world leader in exporting entertainment media content to the world, the U.S. film and television industry must include disabled people and non-stigmatizing disability programming. The goal should be full inclusion in programming, in employment, and with accessibility, Heumann's Ford Foundation report says the goals should be:

- More on-screen representation
- Disabled people comprise around 25% of the characters in media, representative of the one in four Americans who have a disability. Their roles take all forms, from a romantic lead to a dodgy drug dealer to a barista.
- Stories are not centered solely on their disabilities and do not perpetuate harmful stereotypes.
- Nondisabled writers are paired with disabled writers to be sure of authentic representation.
- More people with disabilities work in media at all levels, establishing an ecosystem of disabled people owning, leading, and participating, from executives to showrunners to production assistants.
- There's no more just hiring people who "look like you" – all candidates are given a fair chance based on talent.
- Expertise and resources are universally available, so there can be highly qualified disabled people for the more than 200 career paths in media.
- It is no longer acceptable for people to claim that hiring disabled people is too expensive or too hard.
- Commitments and benchmarks are set by industry groups.
- Industry monitors and provides opportunities for professional development of disabled people.
- All production locations, industry offices, professional development events, etc., are accessible.
- Closed-captioning and video descriptions are standard throughout production.[103]

Entertainment media with disabled performers can lead to progress in the treatment of people with disabilities within society and foster more positive attitudes toward the disability community, according to the United Nations.[104] Positive parasocial effects may occur when disabled actors appear and nondisabled audience members begin to feel affinity with disabled people.[105] Authentic representation may even help stop some discrimination against disabled people.

In Australia, the inclusion of disabled actors (and disabled directors, writers, and crew for film productions) is positioned as the over-arching structure for one filmmaking initiative, Bus Stop Films. It arose from a film student, Genevieve Clay-Smith, who had her first professional job to create a documentary for Down Syndrome NSW, and began to question why no people with Down syndrome were involved. Then she met a talented man with

Down syndrome, Gerard O'Dwyer, who aspired to be an actor and began the process to reconfigure everything she learned in film school into an inclusive filmmaking structure. Clay-Smith said

> One participant, Gerard O'Dwyer, wanted to be an actor. This dream, however, came with complicated challenges; Gerard wanted to enter an industry that was notoriously exclusive and extremely limited in opportunities for people with a disability. To be honest there were no viable pathways for a person with an intellectual disability to gain a job in production. It was simply unheard of.[106]

As she was finishing her final university year in 2008 and about to shoot her major film project for her degree, she decided O'Dwyer would star and other of the adults she met with Down syndrome who wanted to participate would sign on as part of the crew. She prepped her disabled actors and crew by hosting a two-hour filmmaking workshop at a friend's home. Clay-Smith said,

> I believed if I was going to make a film about a person with disability, it should be made with people with disabilities, too. I wanted to put my newfound revelation of inclusion into practice by giving opportunities to people who otherwise might not have the chance to get involved in filmmaking.[107]

The disabled and nondisabled crew and actors worked well together to make the resulting short film, *Be My Brother*.[108] It is a tour de force performance by O'Dwyer, who plays a charmer with a tape recorder at a bus stop who performs dialogue from Shakespeare and *The Lion King* and highlights a character who wants to work but who no one will give a chance. The casual encounter gives two nondisabled people at the bus stop unexpected insights into the many capabilities of a person with a disability. Critic Richard Propes says O'Dwyer "gives a delightful, spirited performance as Richard and it's the kind of performance that makes everything else that unfolds in the film feel honest, true, and completely authentic."[109] In 2009, it won Best Film at the world's largest short film festival, Tropfest, and Gerard O'Dwyer won Best Male Actor.[110] Clay-Smith says the critical success of *Be My Brother* cemented her commitment to inclusive filmmaking: "It made me realise that making work inclusively was not only a good thing to do or the right thing to do, but the work could also be extremely successful in its own right."[111] O'Dwyer has gone on to star in multiple Clay-Smith films and in 2019 appeared in the feature-length comedy-horror film, *Little Monsters*, with Academy Award-winning actress Lupita Nyong'o. O'Dwyer says,

> Genevieve has always believed in my ability as an actor and has taught me that you don't have to be perfect in life to fulfil your dreams. On

> set, Genevieve is very cool, calm and easy going and she treats me with respect, which is important.[112]

The bus stop setting of *Be My Brother* gave name to Clay-Smith's vision to create a structure for inclusive filmmaking at Bus Stop Films, which has both creative and educational components. It states its mission as: "We EDUCATE, CREATE and ADVOCATE. Bus Stop makes films with, for and about people from diverse backgrounds and abilities."[113] Bus Stop Films now has inclusive filmmaking courses all over Australia and produces films starring disabled performers that screen at film festivals worldwide. It released the *Inclusive Filmmaking Toolkit* in 2020 so other productions will know what to do. Teaching and production go hand in hand to create the inclusive filmmaking sets. On the production side, the *Toolkit* recommends adapting tasks in pre-production so people with disabilities can participate, looking at the capabilities of disabled crew members and consider a buddy system and support workers, and making sure people with disabilities are involved in the editing and post-production of the film.[114] In the inclusive creative process, the *Toolkit* says authenticity is paramount, in both writing and acting.

> Consider your storyline and invite members of the relevant disability community into your writers' room. Give this representative your trust. Authenticity in storytelling is a brilliant outcome from inclusion. Furthermore, it ensures your representation of disability, should you be writing on the topic, is authentic and truthful.[115]

The *Toolkit* gives the example of this from their film, *Offspring*, which starred the visually impaired actor Ben Phillips, who told the writers the script by a sighted person was incorrect by having a scene in which a blind person felt someone's face with their hands. The *Toolkit* explains that inauthentic scene could have been avoided with a blind person in the writers' room.

U.S. media arts education researcher and film professor Kyja Kristjansson-Nelson studied the inclusive filmmaking practices of Bus Stop Films in 2019 and reported:

> Within Bus Stop Films, inclusive leadership and inclusive filmmaking, combined with a 'people first' purpose, created an inclusive culture driven by collaboration between team members who are committed to the social impact of their work. At the heart of these relationships, transformation was evident; transformation of students, transformation of industry professionals, and the transformation of audience perspectives.[116]

Kristjansson-Nelson's research about Bus Stop Films concludes that for film industry practices to shift to more inclusion, they will need to focus on creating collaborative productions: "Film and media arts educators may wish to examine programmatic standards for professional practice, as well as pedagogical practices that prioritize aspects of collaboration and inclusion over product and the auteur."[117] Inclusion in filmmaking creates cultural content that also has the potential to change audience attitudes for "broader social change."[118] Full inclusion in filmmaking is the only way to disrupt the ableist stereotypes from nondisabled creators.

Disabled talent having a say

Some mainstream entertainment industry productions are taking some notice of disabled creators and are even writing it into their best practices, often in collaboration with disabled writers, directors, and performers, who are gaining power. For example, in the U.S. entertainment industry, disabled performers like Alan Toy (who became the first wheelchair user to play disabled U.S. President Franklin D. Roosevelt in 2021's TV production of *Annie Live*[119]) and the late Christopher Ann Templeton[120] formed a disability committee within the Screen Actors Guild (SAG) union. Their advocacy led to disability being added into the Affirmative Action/Non-Discrimination Clause of the 1980 Collective Bargaining Agreements of the SAG and the Alliance of Motion Picture and Television Producers (AMPTP).[121] That advocacy created the Media Access Office (MAO) in California, which built relationships between the disability community and entertainment industry. The co-founding director of MAO, Tari Hartman Squire, who has been a long-time public relations and marketing person promoting disability in the entertainment industry, also worked to make journalism more aware of disability by co-authoring the 1993 book, *Making News: How to Get News Coverage of Disability Rights Issues*, with then *Disability Rag* editor Mary Johnson. The MAO had awards to honor "people in the film and television industries who are advancing the accurate portrayals and employment of people with disabilities."[122] Those awards were re-established in 2010 through the efforts of disabled screenwriter Allen Rucker and writer/producer Deborah Calla. Under the umbrella of the Media Access Awards, new guides, *Employing Writers With Disabilities: A Best Practices Guide* (2019),[123] and initiatives work to remind Hollywood to include disabled people accurately and authentically. The Media Access Awards' project, The Disabled List, acts as a kind of disabled writer incubator by identifying scripts that "advance the portrayal of disabilities"[124] for the entertainment industry. One of the sponsors of the project is the U.S. disability services organization Easterseals Southern California. Its CEO Mark Whitley said "Hollywood can play a huge role in empowering the disability community:" 'By highlighting people with disabilities through storytelling, we shape perceptions of this minority group and create a more inclusive society.'"[125]

Easterseals, founded in 1919 to provide services to disabled children, adapted to a more disability equity model in its work as legislation like the 1990 Americans with Disabilities Act sought to empower disabled

Americans.[126] In addition to its support of the Media Access Awards, its Southern California chapter now sponsors the Easterseals Disability Film Challenge, which gives aspiring filmmakers a way to showcase disability. Founded in 2013 by actor/comedian/producer Nic Novicki, who has dwarfism, its structure is this:

> During the Challenge, registered filmmakers – with and without disabilities – are given a span of 55 hours over the designated weekend to write and produce short films (three-to-five minutes) that Help Change the Way We View Disability, which are then judged in four award categories – Best Film, Best Filmmaker, Best Actor and Best Awareness Campaign – by a noted and diverse group of entertainment industry talent.[127]

Novicki describes the need for Film Challenge this way, "to try to create more opportunities for people with disabilities and ultimately change the way people see disability."[128] As a little person, he said he had to try to break into the entertainment industry through writing, shooting, and editing his own independent projects. Novicki has had Hollywood industry success as well, appearing in *The Sopranos* and *Boardwalk Empire*. The Easterseals Disability Film Challenge has expanded, having 10 sponsors now, providing mentoring from industry leader, and giving $2,000 in grants, computers, and cameras.

Digital media executive Anna Pakman, who has CP, has been involved with several disability and media endeavors over the years: Lights! Camera! Access![129] which uses networking events to assist young people with disabilities who aspire to work in mass media, and New York's ReelAbilities Film Festival,[130] which hosts film festivals about authentic disability experiences in 18 locations in North America. But Pakman said she wanted to do even more to improve disability representation so she began creating films for the Challenge in 2020, saying, "I realized that if the content that I wanted to see wasn't being made I needed to be the change I wanted to see in the world and start producing my own work."[131] Her first film, *My Superpower*, is a documentary about her creative partner, Liz Pritchard, who is an autistic artist, advocate, and content creator. Her second film, the mockumentary *Social Fitness* (2021), is about a group of people, with and without disabilities, navigating life after experiencing the Covid-19 pandemic; it won the Best Awareness Campaign from the Challenge. Pakman said *Social Fitness* illustrates that inclusive films make disability representation more authentic

> My approach to casting would be considered revolutionary in Hollywood proper. Seven out of my 10 actors had disabilities, but none of my characters were written as having a specific disability. Yet, my characters are authentically disabled because my actors are, and that's

> exactly what we need: More images of disabled people going to school, getting jobs, having sex, getting married, or parenting. We need to see ourselves as lawyers, doctors, TV writers, reporters, teachers. We need to see ourselves being good at those jobs—and being bad at them too.[132]

Some of the participants in the Easterseals Disability Film Challenge get work on Hollywood productions.

Television productions in several countries are learning to collaborate with disabled talent more. In 2021, Channel 4 in the UK collaborated with disability and media advocacy groups to produce the *Guide to Including Disabled Talent in the TV Industry*, the Disabled Contributors Welfare Guidelines,[133] and its Engage and Enable disability strategy to hire disabled people in all aspects of a production.[134] The U.S. television industry in 2022 included disabled people when it surveyed people who work in that industry about diversity, equity, and inclusion (DEI) practices there, finding:

> Underrepresentation – While there has been reported growth in gender and race/ethnicity representation, members from historically marginalized backgrounds still perceive a lack of sufficient representation, especially for those with intersecting marginalized identities.
>
> Exclusionary Lived Experiences – Members from historically marginalized communities reported significantly more exclusionary and harmful experiences in their workplaces—including microaggressions and harassment—than non-marginalized members. Members from marginalized groups were also more likely to report being undercompensated and even passing on job opportunities due to perceived DEI issues.
>
> Insufficient Action – Members across peer groups and identities noted confidence in their understanding of DEI topics and issues, but only a small percentage perceived impactful actions or progress towards resolving DEI issues at their workplaces and in the industry at large.[135]

Almost 20 years before, the disability committee of the SAG commissioned a study of the experiences of performers with disabilities in the U.S. entertainment industry with strikingly similar results:

> Despite measures such as the Americans with Disabilities Act and the Producers/Screen Actors Guild's Policy of Non-Discrimination and Diversity (2001), 36% of the performers with disabilities felt they had encountered some form of discrimination in the workplace, including not being cast or being refused an audition because of their disability.
>
> While a little over a third of the performers with disabilities stated that a reasonable accommodation would help them in their work, 60% never asked for an accommodation because they believed employers

> would be reluctant to hire them. Many of the performers were unwilling to be candid about their disability in fear of being viewed as an object of pity and incapable of doing the job.
>
> Overall, the respondents believed that their prospects for employment were very limited and identified the three greatest barriers as: (1) only being considered for disability-specific roles; (2) a lack of acting jobs in general; and (3) difficulty getting an audition.[136]

Nic Novicki explains that people with disabilities must be involved with all aspects of TV and film: "True inclusion will happen when people with disabilities have a prominent seat at the creative table. The path forward is expanded employment opportunities for people with disabilities in front of and behind the camera and increased representation of people with disabilities in more storylines."[137]

The involvement of the disability community with its "crip power"[138] is the thing that will transform the film and television narratives. Just as Mitchell and Snyder say "disability scholars and activists should not 'cede the literary field' to the 'retrograde politics of disability,'" so talented disabled people in the TV and film industries are now infusing media narratives with their community's authentic stories. Mitchell and Snyder explain at the end of their book, *Narrative Prosthesis*:

> The constructed cultural estrangement from disabled people's perspectives that have been shrouded in mystery must fall away. Our writers and filmmakers possess the unique opportunity to dismantle our alienating mythologies by risking entry into this seemingly unimaginable or uninhabitable universe.[139]

A good example of this reshaping of the stories of the disability community is the 2022 reboot of *Queer as Folk* on the NBC network's streaming platform, Peacock TV. Canadian podcaster and accessible sex toy inventor Andrew Gurza, who has CP and uses a wheelchair, had a cameo appearance in the Season 1, Episode 4, about an orgy with disabled people, called a "crip rave." Gurza says he "had to be a storyteller in order to be seen."[140] As a disabled queer man, he says he wasn't seen as a possible sex partner in the LGBTQ+ community. The *Queer as Folk* episode that includes Gurzawas written by a gay disabled man, *Special* creator and star, Ryan O'Connell, who is a writer, actor, and co-executive producer of *Queer as Folk*. *Queer as Folk* explores a powerful intersectional narrative that shows disabled people are multifaceted and sexual. O'Connell says, "I just want people to understand that disabled people are sexy and sexual beings, and we've been denied that for so long."[141] In that episode, O'Connell's character has sex with gay Deaf model/actor/producer Nyle DiMarco. The show also explores the Black, disabled, queer experience through the character of Marvin, who is played by Eric Graise. Graise is a singer/actor/dancer who is a double-leg amputee from early childhood.[142] Marvin is the instigator of the crip rave on *Queer as Folk*, and Graise says he was extremely happy with that episode because it showed disabled people being joyful and sexual and not presented as people filled with tragedy or trauma. Graise added:

> It's important to me that the audience sees a fully fleshed-out, rounded character who is complicated, just like the other characters. Marvin isn't just some piece of furniture. I think what happens sometimes with characters written with disabilities is that they're there to be inspirational, and to remind the audience that people with disabilities are sweet and nice. I didn't want that. If that happens, then cool, but it happens so often.[143]

By tapping into the actual disabled and LGBTQ+ community through the members of that community on set, *Queer as Folk* was able to represent a fun and jubilant group of young people, who happened to also be disabled.

Another disability community effort is the musical film *Best Summer Ever* (2020), which holds the distinction of being the first feature-length film to have disabled people working as the majority of its cast and crew.[144] The film grew out of the filmmaking arm of Vermont-based Zeno Mountain Farm, which hosts integrated camps for disabled and nondisabled people of all ages. Zeno reported that its goal for the film, which took two years to make, is to "change the world while singing and dancing." It was Zeno's way of fighting against the U.S. film industry's exclusion of disabled people:

> Hollywood has ignored the disability community all too often and mostly got it wrong. Instead of talking about it, we decided to make a movie that proves to the world that disabled talent needs to be involved in every aspect of film making.[145]

Zeno already had shown its filmmaking prowess with *Finding Zac Efron* (2012) and a documentary about its making a Western, *Becoming Bulletproof* (2014). A Zeno acting camp in Southern California also put together the disabled and nondisabled men who would create *Peanut Butter Falcon* (2019). After becoming friends with Zack Gottsagen at Zeno camps in Southern California, Michael Schwartz and Tyler Nilson wrote *Peanut Butter Falcon* for the actor with Down syndrome.[146] A long-time participant in Zeno camps, Gottsagen collaborated with Schwartz and Nilson to create a feature film partially based on Gottsagen's interest in wrestling. Gottsagen also appears as a cheerleader in *Best Summer Ever*.

Even though *Best Summer Ever* has so many disabled characters, its focus is not on disability but on the lively teen musical storyline (it has eight original songs), which follows teens who fall in love at sleepaway dance camp and discover they will be attending the same high school. Sage (disabled actor Shannon DeVido) and football player Tony (nondisabled actor Rickey

Wilson Jr.) try to continue their relationship among high school mean girls and family pressure for Tony all while keeping his secret that he attended a dance camp and loves to dance. Its lack of discussion of disability was intentional. Its co-director Lauren Smitelli said: "I was interested in showing characters on screen that have disabilities without having that ever become part of the story."[147] *Best Summer Ever* producer Andrew Pilkington, who has CP, agrees, "Just because you have a disabled character doesn't mean the show has to be about their disability."[148] DeVido, who is a wheelchair user due to spinal muscular atrophy (SMA), says that an inclusive set leads to a "welcoming and supportive environment" where the entire production can accomplish their best work. For this film, she adds, "You get something that has heart and joy, and that's something that I think the world needs. We all deserve a seat at the table."[149] Disabled entertainment writer Kristen Lopez says a film filled with disabled people can be exuberant and playful. Her review of *Best Summer Ever* says, "what it does is continue to show that disability can be fun, unique, and enticing without being dour."[150]

In the UK, the BBC now has a policy that says producers creating content about disability should "always use disabled actors for disabled roles."[151] That attention to authenticity has resulted in several British television productions that include disabled people at almost every level. In 2020, *Crip Tales* was a true disability community effort, with the set of monologues written, directed, and acted by disabled people. Creator Mat Fraser, who is a disabled actor/writer/musician, says he wanted *Crip Tales* "to be a wholly disabled experience."[152] He especially wanted disabled directors to get experience shooting the monologues so they can hopefully get more work in the inaccessible industry. "We haven't exactly been welcomed by the industry [and] for disabled directors it's been the hardest shlep of all," Fraser said.[153] In 2022, disabled comedian/writer Laurence Clark had his TV pilot, *Perfect*, win the Dave Channel's All New Laughs: UKTV WriterSlam competition and air in August.[154] It stars disabled actor George Robinson of the dramedy series *Sex Education* (2019–present). In *Perfect*, Robinson plays one of three young disabled people who "become unexpected friends when they meet on a half-cocked and pointless work preparation scheme."[155]

Authentic disability representation comes from hiring disabled actors who bring the ethos of the disability community into their work. Victoria Ann Lewis, who championed disabled writers and performers, including herself, says "disability at a fundamental level is about community and about how we need each other."[156] In her book about the disability justice arts collective, *Sins Invalid*, Shayda Kafai calls this *Crip Kinship* and says that "disabled communities have wisdom" – "we survive true when we declare and cocreate a world that honors us, a world where we are never too much."[157] When disabled talent and media creators tell their stories and when they have a hand in crafting all stories in film and television, even when disability is not a plot point, then all audiences benefit from genuine and new media narratives that no longer perpetuate ableist metaphors. Disabled screenwriter David Radcliff says film and television will be transformed by the better inclusion of the disability community: “These are ambitious, hardworking people that are just left out of the mix. The more we see disabled people on-screen, working jobs, raising families, living productive lives like we’ve seen on *Crip Camp* ... that is beneficial to everybody.”[158] Dismantling narrative prosthesis in the storylines of film and TV through the collaboration of disabled people on set has the potential to “reduce prejudice” against disabled people, says disability and psychology researcher Richard Amm,[159] and it also gives all societies new and engaging narratives from the disability community that are still untold.

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2 Talking the talk of real disabled people's lives

Previously unsure of how the world would embrace her, Rachel Osterbach, who has Down syndrome, starred on the U.S. reality show *Born This Way* from 2015 to 2019 and found the experience gave her confidence in her daily life. Osterbach said rooming with fellow cast member Megan Bomgaars and watching cast member Cristina Sanz get engaged and then married on *Born This Way* helped her feel empowered to move out of her parents' home in Southern California and into her own apartment with support.[1] She continues her journey of living independently even though her parents moved farther away.[2] The show, which featured seven young adults with Down syndrome and their parents, even helped her conquer other fears as well, such as going camping, attending loud rock concerts, and riding horses. Before *Born This Way*, she worked as a clerk at a local insurance office and went back to it after the show the ended. But with her fame as a reality star, she became a motivational speaker and recorded paid celebrity videos on Cameo for her fans.[3] She hinted at an interest in becoming an actor on *Born This Way,* but she says speaking to people fits better with her personality than acting does. From the show, Osterbach says she learned never to give up on her dreams and that is the message she conveys when she gives talks around the U.S.[4]

Osterbach illustrates how reality TV can have a positive impact, especially when people with disabilities are involved in an ethical and authentic manner. Reality television, along with TED Talks, have allowed people with disabilities to share their more authentic lived experiences with audiences around the world, as well as providing information and building connections with those audiences. Australian disability and media scholar Katie Ellis in her *Disability and Popular Culture* book reminds that the reality TV show genre "relies on disability to elicit emotion from the audience."[5] The basis of much reality TV is "the intersection of between voyeurism and cultural entertainment," and disabled stars and contestants fit within audience desires to stare at them, Ellis says.[6] But when disabled people on reality TV have more power, they have more control over what those audiences see and can provide them with insight into their actual lived experiences.

Although this book considers media creators rather than media audiences, research into parasocial interactions from TV and online audiences shows

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that viewing actual disabled people on television can lessen their negative stereotypes about disabilities.[7] From a media creation standpoint, disabled people can better craft their own representation in TED Talks or on reality television. And disabled audience members and disabled participants in these genres may feel empowered by the content. Mass communication scholars Lingling Zhang and Beth Haller's research about disabled media audience members illustrated that people with disabilities can find authentic representations of disability on reality TV empowering to watch.[8]

Reality TV

Much of academia dismisses reality TV as faked histrionics for undiscerning viewers who take vapid pleasure in its drama, but American sociologist Danielle J. Lindemann's 2022 book, *True Story: What Reality TV Says About Us*, argues that reality TV is actually a twisted reflection of U.S. society and its entrenched stereotypes about all the people depicted on reality television. Modern reality TV content may perform much more diversity and inclusion in terms of race, class, gender, sexuality, and even disability, but Lindemann says conservative values still underpin most shows.[9] She writes as a criticism of reality TV: "The experience of watching these shows, like looking in any mirror, is interactive. We see ourselves, and then we groom ourselves accordingly." Lindemann contends this is a negative influence of reality TV. But it can be argued that because of the lack of representation of actual disabled people in television and film, reality TV offers disabled reality TV cast members and their disabled audiences an empowering visibility. Reality TV shows featuring people with disabilities as the primary cast are more authentic than other reality TV shows or even fictional TV, which have long hired non-disabled actors to play disabled characters. American media consultants and filmmakers Dom Evans and Ashtyn Law of FilmDis study disability representation in scripted TV and found in the 2019/2020 season that "out of the 1,198 disabled characters across the 30 networks & streaming services, only 128 characters were portrayed by disabled actors, who had at least one of the disabilities they portrayed."[10] This represents only 11% of scripted TV's disabled characters being played by disabled actors, so reality TV provides a place for the perspectives of actual disabled people.

Born This Way creator Jonathan Murray, the person who developed the modern American reality show, *The Real World* on MTV in 1992, said the whole strategy of reality TV for him was to put diverse people together and see what happens – the friendships and the inevitable conflicts that arise. In the early 1990s, Murray, who had a background producing TV news, joined with business partner, the late Mary-Ellis Bunim, who had a background producing soap operas, to create a scripted soap opera for MTV about young people starting their lives in New York City, but MTV executives decided they didn't want a scripted series, so the two created an unscripted series that they called a "docu-soap."[11] Murray, who is a gay man, told *Abilities* magazine in 2019 that "*The Real World* was about diversity and putting together seven individuals from different backgrounds, different walks of life, socio-economically, sexual orientation, whatever. Because normally you don't find yourself with people who are different than you." Murray explained the formula for the show:

> The idea behind *The Real World* was to put people with different backgrounds together and that there would be conflict, because they would make mistakes with each other, and out of that conflict would come growth, and out of that growth would be our story arc for the show.[12]

One of first cast members on *The Real World* to show the power of reality TV to educate audiences about chronic illnesses and disabilities was the late Pedro Zamora, who was the first openly gay, HIV-positive person on American television when he appeared on the third season of *The Real World: San Francisco* in 1994. Zamora contracted HIV at age 17 and dedicated his time after that to educating people about HIV, both to protect themselves and to fight against the stigma that HIV-positive people face.[13] In his 1994 obituary, Mary-Ellis Bunim, Murray's producing partner, told *People* magazine Zamora's desire to be on the show was not for celebrity status, but for educating people about AIDS: "Pedro wanted to spread his story."[14] Former President Bill Clinton credited Pedro Zamora with helping lessen the fear people had of those with HIV/AIDS through his role on *The Real World* and his public speaking.[15]

But the conflict-infused formula that worked for so many reality shows did not fit as well for people with intellectual disabilities. Murray tried to create *Born This Way* following the "everyone lives in the same house" structure but the U.S. cable network, A&E, passed on the show, believing that its audience demographic of 25–54-year-olds would not be interested. But four years later, A&E reconsidered, and Murray said by that time, he knew he needed not only the young adults with Down syndrome involved but also their parents and other family members.[16]

The idea to focus on people with intellectual disabilities came from a documentary series he saw about a European woman with Down syndrome created by her brother, who works in television news. Because he had several years to think about how to shape *Born This Way* with the A&E audience demographics in mind, Murray said he realized the show would be more interesting if it acknowledged the young adults' journeys toward independence, with supportive family members in the show encouraging them on their paths:

> I had a lot of time to think about it, and one of the things I realized was that we should approach it more as a documentary and that the relationship between someone who has a disability, in this case people with Down syndrome, and their parents is a fascinating thing to explore.

> And in the case of young people with Down syndrome, it was the first generation whose parents had said, 'No, my kid will be mainstreamed. My kid deserves early intervention. What are you doing for my kid? I want my kid to have every advantage they can have because I want them to be ultimately as independent as possible.'[17]

The more documentary style formula worked and the show had four seasons on A&E of 35 episodes total and won three Emmy awards, one of which was for "Outstanding Unstructured Reality Program" in 2016.

> We sort of knew we had something very genuine and very authentic … had to go back to that and trusting the emotion of the scene and that the emotional connection viewers would have with the seven adults would carry through to commercial, and that's very different.

Murray said.[18] He added that after the show's Emmy win: "For too long, people with disabilities, including Down syndrome, have been placed on the sidelines of life – and the margins of primetime. With *Born This Way* airing on A&E, that is no longer the case."[19]

The show lives on in streaming on platforms like Amazon Prime and the A&E Channel, and internationally it is even available as an offering on airline TV offerings.[20] More importantly, the show became an educational tool with A&E developing a *Viewing Guide* for teachers to use the show in classrooms and a *Born This Way Fan Guide* with resources about organizations to assist people with intellectual disabilities.[21] Several high-profile journalists, who have children with Down syndrome, thoughtfully critiqued the show. Historian and writer David Perry, whose son Nico has Down syndrome and autism, says *Born This Way* falls into the usual problematic structures of reality TV but by allowing adults with Down syndrome agency and a voice, it actually pushes back against many of the stereotypes of people with Down syndrome: "We, as a society, tend to regard people with Down syndrome as cute, perpetual children. Seeing adults speak for themselves about adult topics can only help work against this misperception," Perry writes.[22] He points out that Elena Ashmore on *Born This Way* brings reality TV levels of drama, but the show digs deeper to help audiences see that Elena is dealing with the trauma of being rejected in childhood by her Japanese mother, Hiromi. Hiromi admits on the show that she took 20 years to accept Elena having Down syndrome.[23] Elena lives in a group home, but on the show the mother-daughter relationship grows stronger,[24] and Elena becomes more comfortable with her identity as a person with Down syndrome. She writes poetry to express herself[25] and participated in poetry reading events on the show, as well as training as a barista.[26] Perry says his biggest worry about the show is that the adults with Down syndrome are more often on screen with other adults with Down syndrome and their families, instead of being a part of the larger world.[27] That was remedied in later seasons when the show followed the adults to their jobs, such as Rachel's administrative duties at an insurance office.

Former *New York Times* assignment editor Vicki Vila, who has a son with Down syndrome, called it "a very positive and likable show."[28] She interviewed other parents and young adults with Down syndrome, and everyone agreed the show was a mostly positive representation, with a few suggestions to expand the cast such as by adding someone who is nonverbal. Sandra Assimotos McElwee, the mother of Sean McElwee who appeared on *Born This Way*, said even though the show may have skewed toward more communicative and independent people with Down syndrome, it sparked important conversations for its audience. She said:

> Parents of children both with and without Down syndrome are watching the show together and having important discussions about acceptance, abortion, and making friends with people who are different than themselves. There's a multitude of people, previously ignorant, who now are enlightened. Television is the most powerful medium.[29]

Sean has a YouTube Channel and in 2021 interviewed Laura Korkoian, the executive producer of *Born This Way*, who said the set was a fun place to work and that crew members from other shows often contacted her about openings to work on *Born This Way*. Korkoian said the cast transformed her personality to worry less when she saw them trying new things and building new relationships.[30] Jonathan Murray says *Born This Way*'s power was the love expressed in the families that provided an antidote to the negative comments people with Down syndrome and their families often experience. He said:

> You saw an incredible love, and you heard from the parents how much their children had contributed to their lives. And what's so great is, when we hear feedback—emails and letters from women or couples who are told that they'll have a child with Down syndrome, and the dark picture the medical community usually paints—they realize, 'No, there's another possibility.'[31]

Bunim-Murray and Korkoian went on to create *Born For Business* (2021) on Peacock streaming, which features four entrepreneurs with the disabilities of spinal muscular atrophy, lupus, Down syndrome, and anxiety.[32]

Before *Born This Way* aired, a number of other production companies created reality TV shows centered on disabled people. The first to find an audience internationally was the 2009 documentary web series, *The Specials*, from the UK, which focuses on five housemates with intellectual disabilities who were childhood friends. In its format, one of the housemates narrates each episode, and viewers rarely see parents or support staff on camera. The people creating *The Specials*, Katy Lock and Daniel May, took a collaborative approach and showed the rough cut of each episode to the housemates and to the parents of Hilly, who set up the living situation for the five young adults. Lock says the housemates quickly got comfortable with her shooting their lives and that they had control over what would be filmed. "It was made clear to them that they could stop the filming at any point and their support workers were on hand to support them with this," Lock says. "Sometimes, a decision would be made to stop, but most of the time the guys were keen to be filmed and would tell me if they thought I was failing to cover something interesting."[33] Season 1 consisted of ten 10-minute episodes released on the show's website in 2009. Season 1 of *The Specials* won a Webby Award and People's Voice in the Reality category, and the housemates and production team went to New York City for the awards ceremony in 2010.[34] Even though *The Specials* refers to itself as documentary series, everyone saw it as a friendly version of reality TV. One reviewer said:

> Though the show tones down the sensationalism that we've been accustomed to from too much *Bachelor* and Bravo, *The Specials* still uses the *The Real World* as its model. Inner-house romance and friendship rule, minus the evil.[35]

But Lock and May had self-funded Season 1 and had no money to shoot Season 2, but the online series caught the attention of powerful Hollywood executives and celebrities such as the producers of *Game of Thrones*, Carolyn Strauss and D.B. Weiss. Once they confirmed that the episodes could be reconfigured into a half-hour format, they signed on as executive producers for Season 2 to try to find a place for it on American television. Actor Rosie O'Donnell also loved the show and sent the trailer of it to Oprah Winfrey, who quickly agreed to air it on her OWN network. O'Donnell and Winfrey also signed on as executive producers, as Lock and May re-cut Season 1 and shot Season 2, which OWN aired as a marathon of all the episodes at once in September 2014. *The Specials* is more than a reality web series but established a community of fans through its website, so Lock and May never sold the show to the OWN network but licensed it to be shown.[36] Other countries, Spain, Sweden, and parts of Latin America, have also seen *The Specials* through licensing deals. *The Specials* website has subscription-based content on independent living and parenting children with Down syndrome. When the global Covid-19 pandemic hit in 2020, Lock and May decided put the series on YouTube for free[37] so people around the world could watch it; the episodes have hundreds of thousands of views as of the end of 2022.[38]

Another category of U.S. reality show centers people with dwarfism. *Little People Big World* (*LPBW*), which chronicles the lives of the Roloff family in Oregon, premiered on the U.S. cable network TLC in 2006 and continues with a focus on the next generation. Its early success on TLC by drawing good ratings[39] and gathering 16 million cumulative viewers in its first three weeks airing[40] opened the doors for many more shows. The parents, Amy and Matt, both have dwarfism, as does one of their four children, Zach, who is now the adult star of the show with his average-height wife, Tori, and their three children, who all have dwarfism. Amy and Matt Roloff are now divorced and have new partners, who are both featured on the show. The other three Roloff children, Jeremy, Molly, and Jacob, who are all average height, are not participating in the modern iteration of the show.

Amy Roloff said that when they were approached about doing the show, they saw it as a good way to educate the general public about dwarfism. "Nothing had depicted dwarfism in an everyday way," she said in 2010.[41] *LPBW* ushered in a number of reality TV shows about little people such as *The Little Couple* (2009–2019), *7 Little Johnstons* (2013-present), *Little Women LA*, (2014–2019, also shows in NY, Atlanta, and Dallas, *Our Little Family* (2015), *My Little Life* (2018), and *I Am Shauna Rae* (2022). In 2015, Zach Roloff married Tori, and they became one of the three couples on *LPBW*, along with his mother Amy and her new husband Chris Marek, and his father Matt and his girlfriend Caryn. Zach began on reality TV as a teenager, and now that he is a parent, he clearly articulates his childhood experiences as a little person and what he wants for his three children with dwarfism. Because Zach Roloff has more creative control in the show, *LPBW* has begun to educate audiences about little people raising their children with dwarfism.

In season 24, episode 5 in November 2022, Zach discusses their son Jackson, 5, who is a confident child and hasn't yet realized his body is different from others. Zach calls it "childhood innocence" about who they are as little people. "The older they get they are going to start realizing that the world looks at them differently," Zach Roloff says.[42] As a five-year-old, Jackson can still run down the beach and not worry about who might be staring at him; Zach says he wasn't a confident child as Jackson is. Two scenarios might play out with Jackson, Zach says, either that his confidence causes him to be more devastated when he realizes he can't physically keep up with average-height people or he never loses his confidence and sees himself as "the fastest person in the room," whether that is accurate or not. Zach wants to instill confidence and resilience in his children so they can face the average-height world.[43]

In the episode, Zach and Tori Roloff have friends visit from Indiana, Mikey and Jessica Witous, who both have achondroplasia, as does their four-year-old son, Mike. The Roloffs are excited to have Jackson play for several days with another child his age who has dwarfism. Mikey, who grew up in an average-height family, and Zach discuss how they are preparing the boys to understand that they have different bodies. Mikey says he tells Mike, "You're not going to look like grandpa [who is average height]."[44] Zach says he had a gradual realization about his dwarfism as a child: "recognizing that you are different; that you are a dwarf."[45] Mikey tells average-height parents of children with dwarfism:

> Find a way to give them the experience of doing the things that they want and they seek enjoyment in. Don't shelter them from society. Let them be in society. Let them know what society is like and how it will

> treat them, so that they are ready for it when they become an adult on their own.[46]

The Witous parents reveal that they have had two "double dominant" babies, which is a fatal condition. A couple who both have achondroplasia have a 25% chance for having a double dominant baby. (The condition is called homozygous achondroplasia.)[47] They had baby girls: Margo, who lived for two and a half months, and Bernadette, who lived for four days. They said they feel blessed that both girls were able to be home with them in their last days and weeks.[48] It is a heartbreaking episode of reality television but gives excellent information to viewers about what parents with the same kind of dwarfism face. It also spurred Zach to speak out about his three children with dwarfism. The couple has been criticized for bringing more people with dwarfism into the world. "They think it is not good that we procreated and brought more dwarfs into the world 'to suffer,'" Zach says. "But I totally disagree with that. I think people with disabilities have a right to procreate and have family."[49]

In talking to the Witous parents, Tori Roloff discusses the trauma of her miscarriage before their third child, but says nothing compares to the loss of Witous babies. She then refers to her children with dwarfism as "three healthy babies,"[50] which is a powerful rebuke to audience members who might see disabled children as "unhealthy." Mikey Witous says he wants the community of people with dwarfism to talk about the loss of their double dominant babies because he sees it as "a form of therapy for parents." Tori says, "when Mikey and Jess talk about losses, it makes other people feel less alone. It could be a healing and encouraging thing."[51]

That episode had other heartbreaking moments when Zach's father, Matt, reveals that his average-height father, Ron Roloff, 84, died of complications from Covid-19 in Arizona in August 2022.[52] Ron Roloff was diagnosed with lymphocytic leukemia in 2021. Although the many reality shows featuring little people have been mostly viewed as positive, some have criticized these shows as playing into TV audiences' voyeurism about people with different bodies, especially bodies shaped by dwarfism. However, as reality TV has become a fixture on television and streaming platforms around the world, audiences watch for all kinds of reasons beyond voyeurism: common interests with the reality stars; dramatic clashes of personalities; the adorable children featured; or even to learn about a disabling condition. And in terms of people with dwarfism, audiences are gaining knowledge about the condition and the reality of the lives of people with dwarfism. Jennifer Arnold, M.D., a neonatologist with a type of dwarfism called Spondyloepiphyseal Dysplasia Type Strudwick and who is the star of *The Little Couple* (2009–2019), says she had no intention of being on a reality TV show after she and her husband Bill Klein were approached for their wedding to be the pilot of a reality TV show. She changed her mind after she overheard a nondisabled child explain to her mother that Jennifer Arnold is a little person like on *LPBW*.[53] Klein wrote in their co-authored 2015 memoir, *Life is Short (no pun intended)*:

> At the moment Jen heard the little girl 'recognize' her, she realized *Little People Big World* had been doing a great job of breaking down barriers and educating people about vernacular and proper etiquette related to people with skeletal dysplasia. The child had an understanding of Jen's condition as well as respect for Jen, because of the child's exposure to skeletal dysplasia on the show.[54]

This experience illustrated to her that their reality show could be used for education, which is a passion of hers as she now focuses her practice on healthcare simulation to educate everyone about healthcare safety in all medical spaces.[55] Klein, a businessman who put Arnold's medical career first, says he was willing to sign on to a reality TV show because he felt the show could "highlight Jen as she inspires, educates and saves lives, and does it with humility, competence, and compassion."[56] The show was on for ten years and saw the couple go through unsuccessful surrogacy, adopt two children with dwarfism internationally – a boy from China and a girl from India – deal with Arnold's cancer diagnosis while they were in India for the adoption, Klein establishing a retail pet store and inventing pet products, Arnold's simulation work at Texas Children's Hospital, and moves from Texas to Florida (and later Massachusetts), as well as showing the average days of family life with birthdays and swim lessons and Halloween.[57]

Another reality show driven by wheelchair-using women, the Sundance Channel's *Push Girls* (2012–2013), has been the subject of academic research, as well as some controversy within Disability Studies. Because *Push Girls* featured beautiful, somewhat privileged disabled women of Los Angeles, it caused some backlash. However, one of the show's stars, Angela Rockwood, who is an Asian American with quadriplegia, was also a producer on the show. The creator of *LPBW*, Gay Rosenthal, approached Rockwood to do a reality show about her post-car accident life. Rockwood was just starting out as a TV and film actress (*The Fast & the Furious*, 2001) before becoming disabled. *Push Girls* stars Tiphany Adams and Auti Angel are paraplegic and Mia Schaikewitz became disabled at 15 when a vein in her spinal cord ruptured, causing leg paralysis.[58] The four women knew each other from acting classes and have similar attitudes about taking their lives as disabled women in a positive direction. A few years after her accident Rockwood and her then husband actor Dustin Nguyen began working with the Christopher and Dana Reeve Foundation to do minority outreach to the Asian community. Rockwood explains she was trying to combat the stigma about disability in that community: "Asian culture looks down on paralysis. They look at it as a bad omen or bad karma, and they shy away from it."[59]

Angel, who died of invasive breast cancer in March 2022, had her own foundation to help young people; her Save a Soul Foundation mentored at-risk youth.[60] Angel was very open about her life before and after the car accident that disabled her: she was a dancer who toured with Hip Hop artists Eazy E, NWA, and LL Cool J and performed in music videos, but she also became addicted to drugs and landed in jail, where she used her religious faith to turn her life around.[61] Before *Push Girls*, she played a character in *Musical Chairs*, a 2011 film about wheelchair ballroom dancing. On that film set, she made it clear to director Susan Seidelman that she should hire more disabled actors for the disabled characters.[62] Angel also worked as a wheelchair dance consultant on the film.

The women of *Push Girls* wanted to show the world that disabled women can be beautiful, sexy, and pursue their dreams like anyone else. Rockwood hoped the audience would have several takeaways from the show:

> My top three are educating and reminding and inspiring. We *Push Girls* can open up our doors to our world and educate people about our lives. It's not even about the wheelchair. The common denominator is our wheelchair, but it's not about our wheelchair. It's about our spirit and how we live our lives. Then, reminding others that they can get through anything that they put their hearts, souls and desire into.[63]

Disability Studies researchers, fans of the show, and critics of the show all voiced contrasting opinions about *Push Girls* during the two seasons it aired. Using a list of stereotypes about disability confirmed in past media and disability research, American communication and disability researchers Krystan Holtzthum and Donnalyn Pompper's narrative analysis found that the show reinforced several stereotypes that have the potential to "relegate women with disabilities to second-class status."[64] While they say *Push Girls* appeared to embrace the Social Model of Disability, it relied heavily on two main stereotypes, the Sex Object and the Supercrip. They report that

> The show's narrative depends on a careful balance of its leads' emotional and physical pain – and viewers' acceptance of sexual objectification of women with disabilities and celebration of Supercrip imagery. This serves as a subtle blame the 'victim' without actually interrogating harmful stereotypes or society's failure to fully accept people with disability.[65]

Holtzthum, who is a wheelchair user, and Pompper fear that the Sex Object and the Supercrip stereotypes set up a kind of unachievable perfect disabled woman scenario on *Push Girls*. They report:

> Like the model minority stereotype that can lead to psychological pressure for Asian-Americans, the Sex Object and Supercrip representations that fuelled *Push Girls* could hold up a flawed picture for women with

> disabilities who lack financial resources for maintaining an independent and experience-rich lifestyle filled with expensive hairstyles, beauty regimens, and shopping excursions.[66]

However, Women's Studies researcher Laurie Ann Carlson has an almost opposite critique of *Push Girls* by evaluating the show through the Disability Studies lens of interdependence. She says she is investigating how "these female cyborgs, who view their wheelchairs as extensions of themselves, present/discuss their own sexualities."[67] Carlson uses Donna Haraway's 1991 definition of the female cyborg[68] and calls cyborgs "interdependent beings whose very existence requires the acceptance of their variant and shifting connections to other animals, creatures, machines."[69] She explains:

> By calling the female subjects of *Push Girls* cyborgs, I am acknowledging the various interdependent connections their bodies forge with "other friendly selves," as well as recognizing their bodies as a social and material reality. Episode 1 of the show, which is aptly named 'Everyone Stares,' demonstrates that more than just being an assistive aid, the wheelchairs of these women are literal extensions of their bodies. The chairs are accessorized with fabulous leopard and zebra print seats, and various ostentatious rims, like Angel's flame-etched ones. Over the course of Season 1, viewers see the seats, rims, and accessories to these chairs change in accordance with weather and occasion.[70]

Carlson acknowledges the critiques that *Push Girls* invites objectification of women and voyeurism of disabled people but finds it more important that the *Push Girls* women are presented as sexual beings. The show discusses Rockwood's financial need for her boyfriend, Cody, to perform as her personal care attendant when they go on a trip together and the other women discuss miscarriages, infertility, and abortion. Carlson's framework presents a kind of "disability gain" in which the women learn more about their bodies and sexuality because of the insights they have from their disabilities: "These women become comfortable with their own sexualities either despite—or arguably because of—their disabilities."[71] She says *Push Girls* ultimately models interdependence for younger disabled women and its audience members. "It is within this context of sharing, discussing, and helping that this group of disabled women forges their own community, and community is the ultimate form of interdependence," Carlson says.[72]

Deaf creators made it onto reality TV through Academy Award-winning Deaf actor Marlee Matlin and Deaf model/actor/producer Nyle DiMarco. Matlin was the first deaf contestant on *Dancing with the Stars* (*DWTS*) in 2008, and after appearing, networks approached her about a reality show about her own family and her role as a Deaf mom to four hearing children, but she and her husband, who works in law enforcement, were concerned about security issues, so she found another deaf/hearing family to feature in the pilot for the show. Matlin financed and produced a pilot for the reality show idea called, *My Deaf Family*, in 2010. She told the *Los Angeles Times* that deaf and hard of hearing people are a large group in the U.S.,[73] yet no reality TV series showed their lives. Her proposed series would be the story of a Fremont, Calif. family, the Firls. The family of six has two deaf parents, two deaf children, and two hearing children.[74] The oldest son, Jared, who is hearing and was 15 at that time, would narrate the show. Matlin envisioned the show this way:

> I like to think of it as a deaf/hearing version of *Little People, Big World*. It was an idea that grew out of my own family (I have 4 children who are hearing, and I'm their mom who is deaf) and the experiences of my business partner and interpreter, Jack Jason, who is hearing but who grew up with deaf parents. I produced and financed the pilot and shot it fast.[75]

But all the networks passed on her show.[76] Matlin said that the various networks claimed that "they didn't quite know if they could pull it off or even how."[77] When she could not get a network interested, she approached Google, owner of YouTube, to distribute the pilot episode because YouTube added automatic captioning technology at the end of 2009.[78] Matlin's goal in posting the pilot on YouTube was to gather an international audience for her planned reality show so that someone with the funds for a full season of the show could be found.[79] That didn't happen, but eight years later, a revised version of her idea aired from the producers of *Born This Way*, a documentary called *Deaf Out Loud* (2018) that profiled three blended Deaf-hearing families. Matlin was an executive producer of the show. It is infused with Deaf pride and deals with many issues that are faced by people with hearing loss, who account for about 30 million Americans.[80] Many in the documentary do not consider deafness a disability and the born-deaf father of the Posner family, Henry, said so: "We're not handicapped. We're not hearing impaired. We're not disabled. We're just deaf."[81] As one reviewer, Bethany Duarte, explained, to deaf people being deaf is normal. Explaining that the documentary destigmatizes hearing loss, she said, "Communicating via sign language is just as normal as speaking is. Whether the hearing loss was degenerative or a born condition, these individuals show life fully lived and embraced rather than limited."[82]

Deaf model/actor/producer Nyle DiMarco won two reality competition shows, *America's Next Top Model* (*ANTM*) in 2014 and *DWTS* in 2016, and he says his experiences on these shows illustrated to him that as a deaf performer, he needed more control in TV and film productions. He says that he faced discrimination and lack of access on *ANTM* such as the production not hiring a sign language interpreter for several days of shooting the show.[83] He fared a bit better on *DWTS* because his hearing dance partner, Peta Murgatroyd, understood his quest to represent the Deaf community by participating in a reality show centered around music. His final dance for the show explored the oppression Deaf Americans have long faced. He had a particular song in mind for the dance, Disturbed's moody cover of Simon and Garfunkel's "The Sound of Silence" but had to convince the band to give permission to use it. He wrote: "Your song 'Sound of Silence' means so much to me and my Deaf community and that I would love to dance to your song for the finals. I feel this is important for you to know that we the Deaf people underwent a terrible history and we are still stuck in the darkness. The darkness of oppression that your song truly reverberated to me."[84] DiMarco is referencing the banning of sign language at U.S. Deaf schools and the push for oralism for many decades until American Sign Language was understood to be a distinct visual language in 1965.[85]

Like Matlin, networks approached DiMarco about a reality show about his multigenerational Deaf family, but he declined, wanting to pursue his acting career. However, because he could not get significant auditions for scripted TV and films, he added producing to his career. DiMarco writes in his 2022 memoir, *Deaf Utopia*, that his estranged father struggled to get an acting career off the ground because he waited for acting opportunities that rarely came. He told his manager and agent that he wanted to be proactive and help craft media content that accurately represents the Deaf community: "Let's start creating Deaf roles, for myself and other Deaf people out there."[86] DiMarco explained his pivot to producing:

> And so my journey began on the other side of the camera, as a producer. Producers are people who make all the magic happen. Stories get created at their hands. It was the ideal path forward for me – as a producer, I would have the opportunity to tell stories I wanted to tell while also creating con-camera roles for myself and other Deaf actors.[87]

After first being asked to be a paid consultant, he asked instead to be a producer so he would have a say in the Deaf representation in Broadway's 2018 revival of "Children of a Lesser God." DiMarco said at the time he was a producer of the play that the film version of *Children of a Lesser God* (1986) had an impact on him as a deaf child who attended deaf schools and whose first language is ASL: "A reflection of myself. A story that valued me and a story about my community. I'd never experienced that before. It was proof I existed as part of humanity."[88] That producer credit got DiMarco into pitch meetings for a sitcom idea about a Deaf family and then in touch with reality TV producer Eric Evangelista (*Breaking Amish*, 2012),[89] who was producing a reality show about students at Gallaudet University, of which DiMarco is a graduate. Evangelista, who is hearing and wanted to learn about the Deaf community, asked DiMarco to co-executive produce the series. DiMarco successfully led the pitch meeting to Netflix and season 1 of the *Deaf U* began airing on Netflix in October 2020. DiMarco believes his passion for his community and for better Deaf representation is what hooked Netflix. "I love being Deaf so much; I love everything about the uniqueness of my and other Deaf people's existences. I am fascinated by it, and I want to share everything about it with other people," he writes in his memoir.[90] He says *Deaf U* is "a monumental step forward for Deaf people toward better media representation, toward claiming our earned space in Hollywood."[91]

Deaf U was praised by critics for showcasing the experiences of young Deaf people for hearing audiences who know little about the Deaf community and for illustrating that Deaf people have similar lives to hearing people. Disabled entertainment writer Kristen Lopez says, "The stories of the individual students aren't unique—ranging from discussions of sex and dating to issues with parents—but to see it through a deaf lens with such a frankness makes it unique." She adds that the show helps audiences understand the wrong notions they have about the Deaf community and all disability communities. She says the show truly highlights an identity-based community well: "There's a sense of belonging and understanding here that's remarkable to see."[92] A reviewer for *TV Guide* writes that anyone who has lived through the confusing time of transitioning from teenagers to young adults can relate to *Deaf U*. She adds:

> The hook of Deaf U is obviously the inside look at how a community has created a rich and dynamic culture with an identity that the outside world has often only considered a disability, and the show delivers on that front. The reason to stay though is that the true value of the show is in getting to know these students as the beautiful work-in-progresses that they are and get invested in who they are aiming to become.[93]

However, *Deaf U* did receive criticism for its depiction of race, with its missing Black women on the show, and lack of discussion of the racism that the Black Deaf community faces from the two Black men on the show. Lopez writes of this problematic aspect of the show:

> Disability representation in media is still heavily a white man's world, and while *Deaf U* gives us far more of a Black deaf experience here than I've ever seen, the fact that none of them are asked about racism at school is troubling. Furthermore, there are absolutely no Black female students included, almost as if they don't exist at all. The same can be said with any discernible Latino population. Again, it's fantastic that a show like this exists, but it's important not to cast the communities into literal Black and white with nothing in-between.[94]

Gallaudet University, which is in Washington, DC, is 17.4% Black/African American,[95] but the show's lack of focus on racism and Black Deaf culture is even more of an oversight, given that the university is in a U.S. city in which

45.8% of its citizens are Black[96] in a country where 13.6% of people identify as Black/African American.[97] DiMarco says he wants *Deaf U* to feature more stories from diverse Deaf people if the show has a second season: "We would really like to explore more LGBTQIA, BIPOC female, and multi-disability perspectives if people are open to sharing their stories."[98]

Another significant aspect of Deaf U was behind the scenes, where 50% of the production employees are deaf or hard of hearing. DiMarco explains:

> We strongly believe that true representation starts behind the camera and I was grateful that Netflix supported that from the beginning. 30% of the crew, 60% of the story department producers, and 30% of the edit team were all Deaf. To me, it made sense to have Deaf people involved in the making of a series that is about Deaf people and their culture. There are some things that only the Deaf crew could have picked up on, a nuance of a conversation or a change in mood for example. That allowed us to do a deep dive into a rich and underrepresented world rarely seen.[99]

Many of these reality shows focused on communities of disabled or Deaf people have ushered in more disability-focused reality shows. But sometimes these reality shows focused on people with neurological, neurodiverse, or intellectual disabilities raise concerns about perpetuating negative stereotypes because people with these disabilities are not in control of the show. The A&E Network aired a six-episode series about teens with Tourette's syndrome in 2018 called *Raising Tourette's*.[100] A jobseeker with Tourette's and one with autism were featured in Great Britain's docuseries *Employable Me* (2016–2017), which followed disabled and neurodiverse people as they went job hunting. A TV reviewer for *The Guardian,* Sam Wollaston, admitted that he "laughed at" the jobseeker with Tourette's, 52-year-old Paul, because of the funny things he shouted, but the reviewer felt he would get used to Paul's tics. However, Wollaston feels the stereotypical tropes about the neurological conditions depicted and sending them to employment locations that are obviously a bad fit are necessary for the show to have drama and an engaging narrative arc.[101]

To give himself permission to laugh, Wollaston references a *Guardian* video from British youth worker Jess Thom, who has Tourette's syndrome and says "tics can be funny, but people often suppress their laughter for fear of causing offence."[102] She advocates for "having an open conversation about disability and difference… so the barriers between us become smaller."[103] Wollaston argues that a humorless approach to a show on the topic of finding employment for disabled people won't advance that cause:

> If it helps to highlight, and destigmatise, and encourage a wiser, more enlightened approach to recruitment, then that's got to be good. Plus, it's warm, human, moving telly. And funny – I'm not going to feel bad

> about laughing; just because something is about debilitating neurological conditions doesn't mean it needs to be worthy and po-faced.[104]

But *Employable Me* is structured as *about* disabled people, not made *with* disabled people. When the other first season jobseeker, Brett, a 34-year-old on the autism spectrum, secures an appropriate job, Wollaston says he tears up at Brett's thank you speech.[105] A qualified applicant securing a job should not be inspiring but that is how it is framed on *Employable Me*. In Season 2, Alan Borgars, who is a 27-year-old university graduate with autism, is featured in his hometown newspaper in Nottingham, England, and the article has no quote from Borgars, only multiple pictures of him standing near the Rushcliffe Borough Council, where he got a temporary job during election season.[106] The assumption from the UK show's production company, Optomen, appears to begin with the idea that neurological disabilities give people debilitating deficits that must be overcome with Supercrip level "special skills":

> At the series' heart is a radical new emerging idea in science: that neurological conditions shouldn't always be looked at in negative terms. By working with experts such as Director of the Autism Research Centre at Cambridge University, Professor Simon Baron-Cohen, and occupational psychologist, Nancy Doyle, the job seekers are shown how the strengths and unique skillsets that accompany neuro-developmental conditions can be harnessed in order to help land them their dream job.[107]

Australian university honors student Chloe Tata Rattray wrote her thesis on Australia's version of *Employable Me* (2018–2019), as well as on *Love on the Spectrum* (2019–2021), another docuseries by the same producer, Karina Holden. Rattray's analysis found that the docuseries continued negative stereotypes about disability and gender, as well as missing intersectional representation among the show's participants. The Australian version of *Employable Me* had participants with a greater variety of disabilities across its two seasons: autism spectrum disorder, Tourette's Syndrome, epilepsy, cerebral palsy, dwarfism, and Down Syndrome. *Love on the Spectrum* follows people on the autism spectrum as they find their way through dating and relationships. Rattray's textual analysis found that "both series reinforce the medical model of disability, focusing not on social aspects of disability like access and inclusion, but on disability as a 'personal problem' to overcome."[108] She says both series imply that they might go in the direction of the social model of disability but when discussions veer into that territory, they are not explored. It is clear from her analysis that a major problem with both docuseries is that they are created from the perspective of nondisabled and neurotypical people. Tattray writes:

> Several production choices contribute to the stereotypical representation in *Employable Me* and *Love on the Spectrum*. In both series, the

> interviewer rarely asks the participants what people without disability can do to create a more inclusive and accessible world. Instead, both series prioritise the voices of 'experts,' such as doctors, psychologists, support workers, and relationship coaches, who largely provide a perspective influenced by the personal tragedy model of disability. The prioritisation of the opinions of people without disability in both series works to undermine the lived experiences of the main participants, depicting them as unreliable narrators of their own lives.[109]

This creates a voyeur perspective for audiences of the series, who gawk at awkward or even embarrassing scenarios for the disabled people on the show. "The construction and premise of both series position the participants as sources of entertainment, light ridicule, and inspiration porn for the audience," Tattray says.[110] Her analysis deploys Disability Studies scholar Robert McRuer's concept of "compulsory able-bodiedness"[111] by illustrating how the shows' participants contort their lives to conform to unrealistic standards of what society believes being nondisabled is. Tattray writes that

> Neither *Employable Me* nor *Love on the Spectrum* fulfil the progressive objectives of new disability documentary cinema: Both series fall short of representing the diversity of the disability community, and do not encourage the audience to take action against ableist societal barriers.[112]

Parasocial contact through reality content

Although this chapter relies on no audience research, scholars who study parasocial contact in television audiences have confirmed that parasocial interactions with television characters can lessen prejudice against certain marginalized groups. The parasocial contact hypothesis about lessening social prejudice was created in 2005 by Edward Schiappa, Peter B. Gregg, and Dean E. Hewes[113] to better understand how prejudice connects to parasocial interactions and parasocial relationships in which TV audiences develop a feeling that they "know" the performers on programs, a concept developed by Horton and Wohl in the 1950s.[114] The research of Schiappa, Gregg, and Hewes used the parasocial contact hypothesis to examine prejudice against gay men and how that might be lessened by TV programs featuring gay men and gay-presenting men. One of the programs they used was the U.S. Bravo cable reality show *Queer Eye for the Straight Guy* (2003–2006), as well as the scripted HBO TV show *Six Feet Under* and a comedy special by cross-dresser Eddie Izzard. The experiments for the hypothesis implied that the parasocial contact with these TV characters by participants could indicate positive parasocial responses and thus shift the participants' beliefs about gay men for the better.[115]

It seems clear that reality TV featuring disabled people could also lessen stigma about disabilities through parasocial contact; however, research findings are unclear because of the tragedy narrative that many nondisabled people believe about people with disabilities. Dutch researchers Flores Müller, Marlies Klijn, and Liesbet Van Zoonen found that audience members with continued viewing of reality TV shows with cast members with physical impairments could begin to have more positive attitudes about disability. They warn, however, that initial reactions to disabled people in reality TV may be negative because of nondisabled people's fear of disability. They explain that

> This initial fear arousing nature of realistic representations of disability suggests that they may put off exactly the group that most likely benefits from prolonged engagement in the 'parasocial interaction' that they offer: those people with little personal contact with persons with a physical impairment.[116]

Research from American mass media scholars Norman Wong, Kathryn Lookadoo, and Gwendelyn Nesbitt applied the parasocial contact hypothesis to mass media interview content about teen Disney star Demi Lovato's disclosure of her bipolar disorder diagnosis in 2011. Their experiment looked at whether participants would lessen their stigmatizing beliefs about people with bipolar disorder after viewing or reading the interviews with Lovato.[117] Although a television interview, not reality TV, it is probably a good barometer for how audiences respond to content they perceive as "real," in addition to the fact that most reality shows have much content where the cast speaks directly to the camera. In the experiment about Lovato's bipolar disclosure, the research found that participants who watched a TV interview or read a magazine article about her discussing the diagnosis had their "social distance and negative stereotypes toward people with bipolar disorder reduced significantly following exposure to Demi Lovato's disclosure about the disease."[118] Their research also has implications for disabled people who become celebrities through their participation in reality TV and in other types of media performances. Wong, Lookadoo, and Nesbitt report that "the higher the attachment to the celebrity…. the lower the perceived negative stereotypes people had about persons with bipolar disorder."[119] The researchers add that quick social media posts or short video PSA's seem to be less effective than a celebrity with mental health disability discussing the diagnosis in-depth and thus connecting with their audiences. The researchers explain:

> The notion that a celebrity can function as an ambassador appears to be a very real and viable strategy for public-health campaigns about bipolar disorder. When a celebrity is willing to share about their lives, those who feel a connection or bond with them become more sympathetic to those with bipolar disorder. A celebrity can influence someone to rethink negative stereotypes.[120]

This research indicates that the more disabled celebrities who exist in mass media, the better nondisabled audiences are able to forge a parasocial relationship and possibly reduce their stigmatized beliefs about disabilities.

Media effects research by Swiss scholars confirmed in 2014 that media representations of a disabled person can change attitudes of nondisabled people toward disabled persons. Jan Reinhardt, Andrew Pennycott, and Bernd Fellinghauer wanted to gauge attitudes of nondisabled people in an effort to better understand employment discrimination against disabled people in Switzerland.[121] Their research involved showing participants a short clip from the German police drama *SOKO Rhein Man* (2006–2008) about a police detective with paraplegia doing his job by subduing and arresting a robber. They found that nondisabled participants viewing the clip had more positive attitudes toward the eligibility of disabled people for employment. The researchers said:

> This study has shown that unusual media portrayals of disabled protagonists which break with stereotypes in a positive manner can improve attitudes towards disability in the short term, at least in non-disabled audiences. Positive, non-stereotypical media depictions of disability are, however, difficult to conceptualise for media professionals. Media organisations' inclusion of people with disabilities in active roles could be an important means to improve this situation.[122]

Other older studies have looked at the attitude change of audiences after viewing TV characters who are blind,[123] have Down syndrome,[124] or people with disabilities in humorous programming.[125] In terms of news events with disabled people changing audience attitudes, British researchers found that public attitudes toward people with intellectual disabilities changed to being more positive after watching Olympic or Paralympic sports footage.[126] They found that footage of both sporting events led to more positive attitudes toward people with intellectual disabilities. They said the positive attitudes from exposure to the footage from both events may be part of the "feel good" factor of watching high-achieving athletes, whether disabled or not.[127] A case study in 2017 about a documentary about a Paralympic sprinter found that documentary viewers "had more positive attitudes overall toward people with disabilities," when compared to a group in the case study that watched only an Olympics documentary.[128]

Unfortunately, there is little current media effects research to compare the Swiss study to because few communication scholars or Disability Studies scholars conduct media effects research. But qualitative Disability Studies scholars like Carrie Sandahl at the University of Illinois-Chicago and Robert McRuer at George Washington University have given media analysis a term that illustrates a way to deconstruct the ableist framing within mass media: cripping. Sandahl coined the use of "crip" as a verb in 2003 to reflect the similar use of the term "queering," which turns homophobic representations on their head. Sandahl says that "Cripping spins mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects. Both queering and cripping expose the arbitrary delineation between normal and defective and the negative social ramifications of attempts to homogenize humanity."[129]

Disabled people themselves also approve of the education function of reality TV. Towson University graduate student Lauren Humphries conducted research on *Little People, Big World* for her 2011 communication master's thesis and surveyed people with dwarfism who are members of the Little People of America organization.[130] Humphries, who has dwarfism, found that "Little People of America members perceive the *Little People, Big World* series as a realistic, positive representation of individuals and families with dwarfism," showing that "LPA members believe informative documentaries, docu-reality series like *Little People, Big World,* and scripted roles in film, have the greatest ability to create positive perceptions of people with dwarfism among people outside the Little People of America organization."[131] It should be noted that the LPA organizational conferences have been featured on *Little People, Big World* a number of times, and many LPA members know the Roloff family members, who have been part of LPA for many years.

Mass media scholars Lingling Zhang and Beth Haller surveyed people with disabilities around the world in 2014 (although mostly people in North America responded – 71%) and found many disabled people found the show *Little People, Big World* had empowering representations of disability.[132] Respondents evaluated 38 American film or TV programs available at that time, such as the 2009 movie *Adam*, and the TV shows with disabled characters such as *House, Lost,* and *South Park*. Two of the most viewed programs were reality TV shows; they reported that "among all the programs evaluated, the top five programs that were most viewed by people with disabilities were *Extreme Home Makeover* (75%), *House* (62%), *Finding Nemo* (62%), *Little People, Big World* (62%), and *Monk* (59.2%)."[133] Out of those most-viewed program, respondents said *Little People, Big World* was the most empowering (5.33 with 7 being most empowering.)[134]

Authentic television representations can help audience members who are Deaf or disabled feel like the media is paying attention to their community. American health communication scholar Tracy Worrell's 2018 book, *Disability in the Media: Examining Stigma and Identity*, considered the impact of media portrayals of disabled characters on people with those disabilities. She surveyed a group of deaf and hard of hearing adults about the scripted teen drama *Switched at Birth,* which featured numerous Deaf actors. She found that those surveyed felt strong identification with the deaf characters who were also deaf people. They said that the way deaf people were represented on the show was neutral, not positive or negative.[135] Not unsurprisingly, children can also benefit from positive educational messages about disabled people. Research in Nepal looked at children's attitudes after watching *Khushi*

Ko Sansar, an entertainment-education children's TV program that tries to promote better treatment of disabled people. The researchers found that having a positive disabled role model in entertainment-education children's media can advance better treatment of people with disabilities.[136]

TED talks

TED Talks from disabled people are purposefully connected to disabled reality TV stars in this chapter because of the discourse research of Italian English scholar Giuseppina Scotto di Carlo, whose analysis discovered how significant the personal connections of TED speakers to their topics are.[137] Disabled people around the world are connecting to audiences through their TED Talks about their lives and experiences. The 2014 TED Talk of the late Australian disabled writer and comedian Stella Young, "I'm not your inspiration, thank you very much," has been viewed more than 5 million times on the TED website[138] and YouTube,[139] as well as becoming standard viewing for Disability Studies students and sharing by disability rights activists. The 2013 TED Talk of Palestinian American actor Maysoon Zayid, who has cerebral palsy, called "I got 99 problems... palsy is just one," has more than 18 million views on the TED website[140] and YouTube.[141] Audiences learn about her supportive parents and how she faced discrimination in college theater by being told she would not be cast to play a disabled character. British disabled artist Sue Austin's TED Talk confronts audience members beliefs about their association of disability with tragedy by describing how empowered she felt when she received her power wheelchair. Then she created an art piece by putting on scuba gear and floating through an oceanic scene in an underwater wheelchair. Her TED Talk, which has 3 million+ views on the TED website and YouTube is described here:

> When Sue Austin got a power wheelchair, she felt a tremendous sense of freedom — yet others looked at her as though she had lost something. In her art, she conveys the spirit of wonder she feels wheeling through the world. Includes thrilling footage of an underwater wheelchair that lets her explore ocean beds, drifting through schools of fish, floating free in 360 degrees.[142]

Scotto di Carlo's analysis discusses how people giving TED Talks use their personal experiences and connections to the topics to engage the audience, who are more attentive when they understand what is motivating the person giving the TED Talk:

> Personal stories are used by the speaker to establish credibility among the audience, as they are used to introduce the speaker's identity (through 'Who I AM' stories) and the genuine purpose for which the speaker is going to give the talk ('Why I Am Here' stories). 'Who I Am'

> stories reveal who the speaker is as a person. In order to convey trustworthiness and credibility, they are usually told at the beginning of a talk. They are also used to capture the audience's attention, as they can give a powerful insight into what really motivates the speaker. 'Why I Am Here' stories are used to tell not only the general purpose of the talk, but especially to tell the speaker's genuine motivation for being there, in order to create deep empathy with the audience.[143]

She says personal narratives help organize TED talks because they help audiences see the credibility of the speaker. "By appealing to emotions, revealing what they both share as human beings, exhorting the audience to make a change," the speakers bond with audiences.[144]

Many disabled TED speakers signal their credibility through their wheelchairs, short stature, white canes, use of sign language, etc. Even if they have no outward sign of an impairment, they explain their hidden conditions in their Talks. This credibility creates "an emotional bond with the audience."[145] Scotto di Carlo uses the example of Dr. Jill Bolte Taylor's 2008 TED Talk, "My stroke of insight," which has 28 million+ views.[146] In it, the brain researcher discusses her own massive stroke. Scotto di Carlo explains

> In this beautifully orated talk, Bolte gives a very detailed account of her thoughts and emotions, guiding and engaging the audience through the entire scientific process of her stroke and discussing the transcendentalist state she experienced throughout it. Through the aid of visuals and her physical position on stage, the speaker magisterially magnifies the audience's engagement.... Her tone, volume and pace mirror her emotions and the audience can highly empathize with her during her speech. As regards her pace, anxiety is conveyed through a major speed of her path, when she recounts the recognition of moments of danger, for instance:
>
> (35) Then all of a sudden my left hemisphere comes back online and it says to me, 'Hey! We got a problem, we got a problem, we gotta get some help.'
>
> (36) 'Hey! You've got to pay attention, we've got to get help,' and I'm thinking, 'I got to get help, I gotta focus.'[147]

Scotto di Carlo says Bolte Taylor's TED Talk evokes curiosity and empathy in the audience, which is also a method of bringing the audience and speaker together in unity. Scotto di Carlo's research is trying to give scientists information about how they can better convey complex ideas to audiences, but this chapter argues that TED Talks are even more germane to building audience relationships with actual disabled people. She says, "these audience-oriented talks do not concentrate on the speaker's identity and reputation, but on the relationship that the experts have with the content of the talk and on how they are personally involved in the topic of the speech."[148] For disabled people sharing their lives or work through TED Talks, this means that audience members are connecting with completely authentic content created and delivered by disabled people.

Raúl Krauthausen, a leader in German disability rights, produced four TEDx Talks and uses them to tell Germany and the world about his various disability rights projects. Krauthausen, who uses a wheelchair because of osteogenesis imperfecta, has a background in advertising and persuasive communication through his university degree at the Berlin University of Arts and Design. When he was at university, he did research about how disabled people are represented on German television: "I found out there are a lot of clichés and negative representation of people with disabilities."[149] He read about media and disability work in Great Britain and the United States and decided in 2004 to found his organization, Sozialhelden, which means "social heroes" in English. The philosophy behind the organization is that the ideas for changing a society to be more inclusive should come from disabled people themselves. Krauthausen says Sozialhelden is creating campaigns to raising attention and awareness about including disabled people in Germany, and it focuses on persuading entities like the media to better represent the disability community in their content.[150]

In 2012 because the Paralympics were in London, Sozialhelden also developed Leitmedien.de,[151] which is an information portal where journalists can learn how better to write and report on disability issues in Germany. It guides journalists on how not to create clichéd coverage, as well as how to prepare to interview a disabled person. Krauthausen says,

> Because when I was working in the media sector, I realized the journalists wanted to do it right, but they don't know how. Because of so much fear, they don't do it. How can we take them by the hand and help them and guide them away from making the biggest mistakes.[152]

The initiative continues through giving workshops to media companies.

Sozialhelden also has a project trying to make the world more accessible for people with mobility disabilities. In 2010, it began Wheelmap.org, which is a free, crowd-sourced online map of wheelchair-accessible locations worldwide. "Anyone can contribute and mark public places around the world according to their wheelchair accessibility," according to Wheelmap.[153] The site now has more than 1 million locations ranked, with the most contributions from Germany, the U.S., India, and France. The Wheelmap app is available in 32 languages and has three rankings: green for fully accessible, yellow for partially accessible, and red for not accessible. Because Germany only has accessibility requirements for public buildings, Wheelmap is putting gentle pressure on getting the private sector, restaurants, bars, and stores to become accessible.[154]

Krauthausen's four TEDx Talks are about Wheelmap (two in Berlin,[155] with one for young people[156]), accessible cities (Hamburg),[157] and equal employment for disabled people (Münster);[158] three of his TEDx Talks are in German (one with English captions) and one in English. As Scotto di Carlo's analysis of TED Talks shows, Krauthausen engages his audience right away in his Wheelmap Talk in Berlin; the audience can see he is a wheelchair user, but he begins by telling them that he has the same questions about disabled people as they do when he meets them on the street: What is their disability? How do they navigate the world? Do they have job? Do they have a partner? But he then reminds the audience that they rarely see as many wheelchair users as exist in society because of lack of access. He gives a quick lesson in German disability history, explaining that after World War II. disabled people were put into institutions, "special" schools, and "special" job training, so they lived apart from the general population. Krauthausen says disabled people are literally on "the fringes of society" because these locations were typically right outside urban centers. Because of their segregated lives, disabled Germans "don't show up in our everyday life," he says.[159] Although Krauthausen went to inclusive schools throughout his education, he says he still faces "a brutal world" because Berlin is so inaccessible. He estimates that about 70% of Berlin's stores have at least two steps, which means he cannot enter. Wheelmap was born when it dawned on Sozialhelden that the 1.6 million wheelchair users in Germany probably knew which businesses were accessible. He reminds his TEDx audience that accessibility is everyone's concern because most people will experience some form of disability in their lives.

Krauthausen also has his own personal media project since 2015, an online television show called "*KRAUTHAUSEN – face to face*." On the show, he has discussions with artists, cultural workers, and media people both with and without disabilities. The show's YouTube description says, "In *face to face* talks, Krauthausen exchanges ideas with his respective guest about artistic work, personal interests and attitudes to life. And of course it's also about #inclusion from time to time."[160] He tackles in-depth topics about arts and culture for disabled people in Germany such as the lack of accessible training for disabled people who want to become actors. Krauthausen says disabled Germans can't go to acting school there because the schools aren't accessible, and if a disabled person without training is hired as an actor, their performance may not be as good as a nondisabled actor who went to acting school. This issue needs to be discussed, he says, because lesser quality performances are due to the exclusion of disabled people from acting programs, not because they have a disability.[161]

Conclusions

It is clear that many disabled people globally have used their reality star status and their TED Talks to spread the word about their experiences and projects. This video content controlled primarily by disabled people is possibly fostering a new anti-ableist way of understanding disability in the world. And nondisabled people are interested, judging from the many millions of people who watch these reality shows and TED Talks. When *Little People, Big World* and *Push Girls* came onto American television, "these reality shows had good ratings and proved to TV executives that TV audiences are interested in lives of people with disabilities, whether they have a connection to disability or not."[162]

Rachel Osterbach of *Born This Way* had her life positively transformed by being on the show through the confidence it gave her. She continues to work for a Southern California insurance office as a part-time clerical assistant and live independently in her own apartment since 2020, with a work-from-home roommate to assist her.[163] She and John Tucker, also from *Born This Way*, became the first people with Down syndrome to present an Emmy in 2017.[164]

Australian media and disability scholar Katie Ellis remind us of the argument of pop culture theorist John Fiske that even though many popular texts "reinforce the status quo,"[165] they also illustrate how social values change over time and how the meanings can adapt. So through reality TV, audiences do learn some accurate information about how disabled people journey through the world, and this can be interpreted as a positive step forward. As Ellis says that "where television fails as a radical text, it succeeds as a progressive one."[166]

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3 Disability content through podcasting and vlogging as public pedagogy

Canadian podcaster Andrew Gurza is on a mission for the world to know that disabled people are sexual beings. Gurza has cerebral palsy and began his podcast, Disability After Dark, to discuss sexual intimacy and access for the disability community. It has now expanded into broader discussions of disability rights, as well as sexual products. Gurza and his sister designed an accessible sex toy through their company, Bumpin.

Gurza, who identifies as a queer man and is wheelchair user, started the podcast in 2016 for several reasons: to highlight the issue of sexuality and disability and to turn his written articles into audio content, which was a bit more accessible for him to produce. Gurza says that its name, Disability After Dark, meant "a podcast shining a light on sex and disability…it's morphed into a podcast shining a light on disability stories, because I think those stories are things that we don't talk about," bringing conversations about disability generally into the light.[1] His podcast episodes in recent years have been about a variety of topics, everything from the lack of accessible housing in Halifax, Nova Scotia, Canada, to an interview with the late U.S. disability rights pioneer Judith Heumann.

Gurza calls himself "Queer Cripple," explaining that because his body is not the typical one for a gay man, he doesn't want to adhere to "narrow homonormative boxes."[2] As for the term "cripple," he only uses it for himself, not other disabled people:

> 'Cripple,' when I use it, allows me to take ownership of everyone's misconceptions of disability; it allows me to pre-emptively say, 'I know what you may think about disability. I know that you're scared of me; I know you think I'm different from you, and guess what? I am.' I'm owning that as best as I can when I use that word. It is a term of personal empowerment for me.[3]

Gurza is also a disability awareness consultant and has been a guest on sex advice podcaster Dan Savage's Lovecast[4] several times to help answer disabled people's sex questions. Gurza says he is trying to address the invisibility of disabled people as sexual beings and to call out ableism in the LBGTQ+ community.

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> Ableism works its way into the queer community,' he says, 'because we have a very specific aesthetic that we adhere to very rigidly. The disabled body doesn't follow that, so we're not seen in magazines. We're not seen in queer porn. We're not seen in the queer clubs on the go-go dance box. We're not seen in all these popular places where queer people — especially, in my case, queer men — go to grow their own knowledge of queerness.[5]

Gurza now puts his content on multiple social media platforms, as many disabled influencers do. In 2019, his hashtag #DisabledPeopleAreHot went viral and has been tweeted 3 million+ times. He says he received mostly positive feedback about it, adding that even the negative reactions mean he hit an ableist nerve with the hashtag. Gurza explains, "I feel the negativity is just proof that the hashtag hit a nerve and is doing its job by exposing all the ableism in our society – particularly around how the disabled body is 'supposed' to be consumed."[6] Gurza is just one example of the hundreds (maybe thousands) of disability podcasts worldwide.

Podcasts as public pedagogy

Podcasting generally is seen by many as the future of storytelling because "it is the instinct of the medium's savvy creators to exploit the same luxury afforded in digital video: freedom. Freedom from a network programming clock, and freedom from broadcast."[7] Many communities internationally have embraced the freedom that comes from podcasting and YouTubing. In Vietnam, Zimbabwe, and China, podcasting allows people to air views in a way that will not be censored by the government. Vietnam podcast editor Quyên Ngô said: "We operate independent of state approval, and we are in support of de-facto free media – voices that sit outside state control."[8] Technology journalist Mark Frary writes that podcasting can allow a voice for people in countries with a high level of censorship of media:

> For those wanting to express themselves freely without interference from the state, it is easy to see the appeal of recording something on your smartphone and uploading it to the web over a virtual private network, attaching it to an encrypted email or copying it to a USB drive that can be placed in another person's hand. It certainly draws less attention than erecting a radio transmitter, buying studio equipment and broadcasting live over closely monitored airwaves.[9]

In other countries with more open mass media, marginalized communities use podcasting to highlight their communities who are often either stigmatized or ignored by mainstream mass media. A team of U.S. podcast and radio researchers studied The Read, The Nod, and Still Processing podcasts from the U.S. Black community[10] and found Black podcasters use the platform to discuss issues that Black people face that are overlooked by the primarily white mainstream news.

> Black podcasts recreate through digital audio space a nuanced sense of African-American trends, cultures, and lifestyles, which are now accessible to non-Black audiences. The effect has opened Black discourse on the meaning of blackness in U.S. culture to an audience of unprecedented scope and diversity.[11]

In their research on Black podcasters, they apply Canadian global television scholar Henry Giroux's concept of public pedagogy[12] by arguing that those podcasts are "educational tools" about U.S. Black culture for their listeners. Giroux explains that societies can bolster their democracies when citizens use new forms of online media that are not part of capitalistic media structures that shut out many voices. Giroux says new online media platforms are "creating non-commodified public spheres and forums that could provide the conditions for critical education"[13] of a society's citizens. Giroux states

> Where the liberatory possibilities of the next generation of media technologies become significant is in the efforts of individuals, groups, and institutions to deploy the pedagogical potential of the new media in constructing new knowledge, including new voices in the conversation, forging alliances across national boundaries, and protecting those public spheres.[14]

In a similar way, disabled podcasters and disabled YouTubers/vloggers are also educating the world with their views and experiences as a similar form of public pedagogy.

Disability podcasts benefit not only their nondisabled audiences but also disabled people who access them can feel empowered by the voices from their community. U.S. disabled writer and blogger Andrew Pulrang explains the importance of disability podcasts:

> So many disabled people still lack practical access to the information, ideas, and culture shared by more connected members of the disability community. And until fairly recently, disabled people with something to share had few outlets to do so on any kind of meaningful scale.… Podcasting offers a unique and particularly enriching way for disabled people get information, emotional enrichment, and a more personal sense of connection, all from their own homes and devices.[15]

These podcasts are educating everyone who listens with their disability content. U.S. filmmaker Cheryl Green, who is disabled from a traumatic brain injury (TBI), was an early creator of audio content – from the phone to streaming radio to podcasting to YouTube videos of her podcast, Pigeonhole. She explains that around 2013 she began her audio journey:

> I had a streaming radio show just all on the telephone, on the Internet. It was these long-form interviews, no editing, no music, no nothing. And I did that for a few years. And I don't remember most of my life, so I just can't really remember how it happened that I started learning about editing and switched over just to the podcast format. And my podcast currently [2021] is called Pigeonhole. It's sometimes I have interviews, but it's mostly stories, some sound design. Everything is disability-focused, disability culture. I don't have any non-disabled people on the show by design. And it's very non-medical; it's very much disability culture and multi-faceted.[16]

U.S. disabled activist/writer/media maker Alice Wong's podcast from 2017 to January 2021 for her Disability Visibility Project amplified her already strong voice for the disability community. She edited collections of disabled people writings, *Disability Visibility, First-Person Stories from the Twenty-First Century*[17] and *Resistance and Hope: Essays by Disabled People*[18] and appeared in mainstream media such as CNN's "United Shades of America" with host W. Kamau Bell.

When Wong began her podcast, she told her audience that she was starting it because even with literally millions of podcasts available (2.4 million globally by August 2022[19]), there were few that touched on significant disability issues or disability at all. "The short answer is that I don't see shows about disability culture and politics from NPR or other major media organizations. There aren't that many around," Wong passionately explained. "The revolution is here. One podcast, one transcript, one tweet at a time."[20]

Wong says it took her four months to produce one podcast episode and its written transcript. Wong, who is a wheelchair user with spinal muscular atrophy (SMA), says it is a disability accommodation for disabled people to use the time they need to accomplish tasks.

> Because I'm working with audio producers. I'm making sure that I have my text transcript. I have all these little elements that I wanna put together, and I have the luxury of not being a fancy-shmancy kind of podcast on a network or on a radio enough. Because, you know, I have control over my schedule and my workflow.[21]

Cheryl Green applauds Wong's disability justice work, especially for BIPOC people, through podcasting. Green told Wong on her last podcast:

> I remember feeling, physically, this wave come over me of relief and like fresh air when I found out that you were going to be doing a podcast.

> I love the way you do politics. I love the way you do culture. I love the way you center BIPOC communities.[22]

Even though Wong stopped producing her podcast, she is assisting other disabled people who want to start a podcast. In 2022, the Disability Visibility Project funded disabled podcasters Thomas Reid, who is a Black blind man, and Green "to develop a resource hub for disabled podcast creators to find each other and audiences."[23] Reid creates audio content at Reid My Mind, which has "stories & profiles of compelling people impacted by all degrees of blindness and disability."[24] He is also an advocate for better audio description on all media content.

Disabled podcasters are not just in North America. The BBC in the UK launched one of the early audio shows about disability issues, BBC Ouch!: Disability Talk, which began as an online magazine-style website in 2002 and became a podcast in 2006, edited by Damon Rose.[25] Rose, who is blind, worked in the BBC's Disabilities Programs Unit in 2002, and Ouch! began from there.[26] In 2022, Ouch! became BBC Access All,[27] which has news and videos about disability topics, as well as a disability news podcast, presented each week by Nikki Fox, who uses a mobility scooter. Inclusion Europe Radio produces podcasts about the inclusion of people with intellectual disabilities, "stories of everyday inclusion experienced and told by self-advocates and family members across Europe."[28] The Disability Crosses Borders podcast and blog from New Zealand explores the experiences of disabled migrants. Hosted by disabled migrant Áine Kelly-Costello, who is a blind freelance writer/journalist and campaigner, the podcast and blog seek to highlight the complex lives of disabled people who must traverse multiple countries and cultures

> This podcast and blog are a home for the stories where disability, migration and culture meet. Moving and living between places and cultures can be exhilarating and overwhelming, fruitful and stressful. When we add disability to the mix, it's even more complex. For disabled migrants and those living between cultures, too often our stories and rights are invisible in immigration conversations, and invisible in disability conversations….
>
> As disabled migrants, asylum seekers, refugees and people living between cultures, I want us to have a safe and constructive forum to share our lived experience and to find community through mapping our collective struggles and wisdom. That includes naming the policies, prejudices and systems that have failed us, talking about how they developed, and how we can change them.[29]

In addition to diverse topics about disability and many resources for the disability community, Alice Wong points out how powerful disability podcasts can be when they live online forever:

> What's really exciting about podcasting or just anything that's posted online is that we really don't know where it'll go, who it'll reach, and that's exciting. 'Cause there's this infinite potential out there that someday, somebody might discover an episode 5, 10 years down the line, and it just might spark something in them. And that, to me, is really what it's all about. It's just putting something out there in the world for everyone.[30]

The public pedagogy function of these podcasts is clear. Wong's radio producer consultant, Geraldine Ah-Sue, added that disability podcasts not only give the disability community an educational tool but also strengthen the community itself: "In a real, fundamental way, it's a real resource for people to learn from and for people to really consider and listen to, if not identify with and feel support and camaraderie with."[31] The disability community built by audio also is supported by many disabled vloggers and YouTubers.

Online video invites participation

Although YouTube has only existed since 2005, it has been a significant site of participatory culture that allows many disabled people worldwide to be included. As an open access video sharing site, YouTube scholars Jean Burgess and Joshua Green say the site was founded to be a place that "would remove technical barriers faced by non-expert users who wanted to share video on the web."[32] The founders wanted it "to become the primary outlet of user-generated content on the Internet, and to allow anyone to upload, share, and browse this content."[33] By 2017, it had become a global powerhouse with 85% of its visitors coming from outside the United States. "YouTube's sheer size and mainstream popularity remain unprecedented."[34]

Disabled people began posting videos and vlogging just like their non-disabled counterparts, especially teens with disabilities. An early disabled YouTuber is Ricky Berwick, who began posting videos at the age of 14 in 2006, but he had little success getting views for his social media content in the early years and stopped posting for nine years. A Canadian, Berwick has Beals-Hecht syndrome, which is a physical disability affecting movement. In 2016, he posted a video of himself yelling and eating French fries that went viral and launched his YouTube sensation status. After that, he appeared on the Comedy Central show, *Tosh.O*, and his YouTube channel began gaining views and subscribers (3.5 million subscribers as of October 2022). But Berwick says he is a comedic entertainer, not a disability advocate, and some disability advocates find his videos degrading. He uses his disabled body for comedic effect in his videos, and Berwick says his goal is "to make people laugh. 'I don't think sticking out your tongue, drooling and eating cookies is helping the world, but it is making the world happy and laughing a lot,'" he told his hometown news site in Kitchner, Ontario, Canada.[35]

Donna Lee, a graduate student at York University in Toronto, Canada, analyzed the content of four vlogs of disabled teen girls on YouTube in 2012 and found that these vlogs

- Produced alternative representations of disabled girlhood
- Constructed disability identity through vlogging
- Allowed the disabled teen girls to construct and perform gender and sexual identity
- Consciously disrupted ableist representations[36]

Lee reported:

> The variety of representations among and across these vloggers challenges the media's portrayal of a single disabled girlhood and reveals multiple disabled girlhoods that are not based on specific impairments but rather on the diversity of experiences, circumstances, affiliations and personalities that disabled girls embody. The pride each of the vloggers takes in a disabled identity is in itself a challenge to the notion often presented in mainstream media that impairment is something to be fixed, overcome or hidden.[37]

One of the disabled teen girls in Lee's research was Southern Californian Laura Martinez, who had muscular dystrophy and used a ventilator and wheelchair. She created hip hop songs in her videos under the name of Cripple with Swag and later MC Meals on Wheels. (She died in 2012 at age 19.) Martinez is most famous for her song, "Vagina Aint Handicapped,"[38] which got more than 1 million views. It was later covered by the U.S. disability music group, Wheelchair Sports Camp.

Australian music and disability scholar Anthea Skinner argues that Martinez' song '"Vagina Aint Handicapped' is a protest against the assumption that a disabled person is incapable of sexual expression."[39] Skinner notes the sound effect of Martinez' ventilator, which created its own rhythm in the song.

> Martinez can be heard gasping for air and at times almost spitting out the lyrics, but she continues regardless, determined to get across her message of sexual capability. In the chorus she acknowledges some of the physical effects of her disability, including those on her [high-pitched] voice, while at the same time asserting that they do not impact on her sexuality.[40]

Skinner writes that the song allows Martinez to call out nondisabled people ("normies" as she calls them) for their ableist behaviors and beliefs. It is about empowerment, according to Skinner, and seeing disabled people as sexual beings. She says that "by depicting a young, disabled woman eagerly participating in a variety of sexual activities, 'Vagina Aint Handicapped' clearly breaks through society's expectations of the disabled body as asexual."[41] The song, and other sexuality content from disabled YouTubers, is a kind of crip sex education through the public pedagogy of YouTube.

YouTubers Squirmy and Grubs, Shane Burcaw and Hannah Aylward Burcaw, call themselves an interabled couple and also educate their viewers about accessibility, ableism, and their relationship as a disabled man and a nondisabled woman. They say they want to change the narrative of disability

> We share our love story with the world in hopes of changing the way society thinks about disability. Far too often, our relationship is perceived by others as remarkable, bizarre, tragic, and unrealistic, but these perceptions originate from a flawed—and extremely damaging—understanding of disability. If one takes the time to look a little deeper, they'll see that our relationship is really no different than any other.[42]

In 2011, Shane, who has SMA, began an anonymous blog on a whim to capture the humor that always existed in his family and among his friends; he called it "Laughing at My Nightmare." Two years later, *The Office* actor Rainn Wilson featured Shane in a video on his Soul Pancake platform.[43] Shane's blog, which had 170,000 followers by the time it was two years old, led to a book deal to write a memoir of the same name. He got more opportunities to be a public speaker and that propelled him to become a disability advocate and start his own non-profit, Laughing at My Nightmare, Inc., which raises money for muscular dystrophy research.[44]

> I decided that I would use the attention to advocate for people with disabilities. A lot of advocating has to do with simply letting people know that people like me exist in the world and sharing stories of me navigating it,

he says.[45]

The Soul Pancake video about Shane in 2013 also led to another major event: A Minnesota college student, Hannah Aylward, saw the video and sent him the email that would begin their long-distance friendship and subsequently their love story. They married in 2020. After they moved in together, they decided to start a YouTube channel.

> We were doing some upcoming travel and traveling with a disability is always rife with challenges, so we figured we should document it in our humorous tone. We named our channel Squirmy and Grubs, which are the (slightly embarrassing) nicknames that we gave each other early in our relationship. We never expected the channel to take off in the way that it did.[46]

The couple's breakthrough came from another YouTube channel focused on showing the experiences of disabled people, Special Books for Special Kids (SBSK).[47] American schoolteacher Chris Ulmer, who created of SBSK, says he is using the channel to try to promote inclusion of people with disabilities in society. It began as videos for parents of disabled kids in his Jacksonville, Florida, elementary school classroom and then it became a blog and Facebook page, with many disabled people asking to be interviewed by him. The YouTube channel began in 2015, had 750 million+ video views, and 3.3 million subscribers by November of 2022.[48] "SBSK is now a 501(c)3 organization that seeks to normalize the diversity of the human condition under the pillars of honesty, respect, mindfulness, positivity and collaboration," according to the channel. "This multi-media movement supports the acceptance and inclusion of all members of the neurodiverse/disability community regardless of diagnosis, age, race, religion, income, sexual orientation, gender or gender expression."[49] Through SBSK, Ulmer has raised more than $1 million in aid for the disabled people he interviews.

The SBSK Channel did a video featuring the Burcaws that went viral and helped their online presence. Called "A Day in the Life of Interabled Lovers," the SBSK video on March 7, 2019 had more than 9.8 million views and more than 2,000 comments as of November 2022.[50] The video introduced its viewers to the reality of the Burcaws relationship: Hannah is Shane's day-to-day caregiver as well as his romantic partner. Many of the comments on the video are from people who admire the couple's loving relationship and from fellow disabled people who wish they could find a romantic partner who would accept their disability. Squirmy and Grubs discuss their romantic life and intimacy in many video interviews and on their own YouTube channel. Shane said in an interview for the Caregiving YouTube Channel that Hannah being his caregiver increases their intimacy because they must have open communication about everything.[51] Online haters, however, have long questioned why a classically beautiful young woman like Hannah would be with a significantly disabled man. Hannah told the *New York Post* in 2022: "We definitely get a lot of comments from straight men thinking that it's not fair that I'm with Shane and that I should be with them. People say that I couldn't possibly be satisfied; we get that every day."[52] But she says Shane uses his voice for intimacy in a way that others might use physical movement. The couple even shot a video in their underwear called "Laughing at Your Ableist BS," where they explained their deep intimacy and comfort with each other. Shane says,

> I know that our life will continue to be hilarious and fun and full of adventure. I feel for the first time in my life that I'm not a burden because Hannah is wholly there for me and doesn't feel burdened by me.[53]

Their authenticity and openness with their viewers on their YouTube Channel has led to its more than 1 million subscribers. The Squirmy and Grubs channel is another good example of public pedagogy through YouTube, and the couple even states their educational focus on their website: "In everything that we do, our goal is to normalize the disability experience. We strive to educate while we entertain."[54]

Their audiences confirm the public pedagogy of the Squirmy and Grubs YouTube Channel. The Disabled Students Association (DSA) co-leader at Bowdoin College in Maine, Matt Hikida, said in 2021 that he wanted the College to host the couple to help change perceptions of disability:

> I feel like, especially during the pandemic, disability has been seen in a really negative light. And I feel like it's just been talked about as this bad, scary thing that makes you more susceptible to COVID [-19] or makes you less available to online learning,' Hikida said. 'I'm excited to have Squirmy and Grubs come … and educate the general Bowdoin population on what it means to be disabled.[55]

Shane Burcaw ended the presentation at Bowdoin, encouraging others, especially other disabled people, to be changemakers in improving society's understanding of the disability experience. "Make your voice heard—and I say this one directly to disabled people. We need more representation out there," Burcaw said. "I'm not saying [to] make a YouTube channel, but do what you can to share your story and inform the people in your life about what your real lived experience is like."[56]

Many other disabled people are leveraging YouTube to teach the world about their experiences. Researchers Woosuk Seo and Hyunggu Jung investigated the experiences of blind or visually impaired (BVI) people who use YouTube to vlog about their lives. They found that:

> BVI vloggers use YouTube as an educational tool. While BVI vloggers educated non-BVI people about blindness or visual impairment by sharing their stories through videos, the videos on YouTube enabled BVI viewers to learn tips for overcoming accessibility issues in their daily lives. In addition, our findings revealed that BVI people create, edit, upload, share, and watch videos on YouTube as non-BVI people do.[57]

Their research discusses the ongoing accessibility issues the BVI vloggers face and suggest that designers do more to create ways to aid BVI vloggers on YouTube. American Sam Seavey's YouTube Channel, The Blind Life, seeks to highlight low vision accessibility while he shares his everyday life with his viewers. He was diagnosed with Stargardt's Disease, a form of macular degeneration when he was 11, and became legally blind by his mid-teens. His channel has more than 48,000 subscribers and 500+ videos.[58] Seavey even has a line of blindness-themed merchandise, illustrating that branding as a disabled YouTuber can lead to merchandizing opportunities just like for nondisabled YouTubers.

Disabled people who are more comfortable conveying information through video, rather than writing or audio, have also found YouTube and other online video platforms useful. The Wisconsin Board for People with Developmental Disabilities began the Self-Determination Channel in 2019. It is a YouTube channel from people with developmental or intellectual disabilities. "Self-advocates host the videos, and decide and create the content," with a theme of empowerment, the Wisconsin Board says. One of its four hosts is a journalism graduate with cerebral palsy, Stacy Ellingen, who uses an app on her phone to communicate.[59]

> It was started to give self-advocates a place where they can be seen and heard, connect with others, and mentor each other. Our hope is that the channel can be used as a teaching tool and show examples of what is possible. Videos are being produced on topics self-advocates care about such as technology, employment, caregivers, living on one's own and advocacy.[60]

Ellingen also runs the Self-Determination Network,[61] which promotes "self-determination by working together to understand, implement and create rewarding lives for elders & citizens with disabilities."[62] She says she speaks out on the Self Determination YouTube channel because "I've always felt that one of my purposes in life is to show others what people with disabilities can do."[63]

A variety of Deaf or disabled people also present news from their communities via a YouTube channel. As a visual medium, YouTube is a perfect platform for sign language. American Alex Abenchuchan, a Deaf man, created The Daily Moth video news site in 2015 and says he infuses his videos with the Deaf perspective on the news.[64] He uses American Sign Language (ASL) to brief his audience about all news, with an emphasis on news happening in the Deaf community. The Daily Moth YouTube channel, which has 49,000+ subscribers and more than 21.5 million views,[65] says that he "covers trending stories and Deaf topics with a twist of humor and Deaf culture."[66] A *Christian Science Monitor* story about the site in 2020 explained that The Daily Moth is about making news content truly accessible to any Deaf person who watches it:

> From closed captions on his videos to the color of his backdrop and his shirt, Mr. Abenchuchan's news is designed to be accessible for deaf, DeafBlind, as well as hearing and sighted people. But his work is also about telling a good story – and striving for credibility – like any other journalist.[67]

Stacy Nowak, a professor of communication at Gallaudet University in Washington, D.C., a university for deaf and hard of hearing people, says The

Daily Moth is unique. “There has never been anything like The Daily Moth before. And in some instances, it really saves [deaf people’s] lives, because they have access to news they can finally understand.”[68]

In Nairobi, Signs Media Kenya Limited has a similar focus on making media content accessible to the Kenyan Deaf community. It launched in 2011 using a social enterprise model “with the main objectives being to educate, inform and entertain in sign language by extension enhancing Disability and the Deaf Culture.” For founder Luke Kizito Muleka, who is hearing but fluent in sign language, creating a sign language channel was a way to give equal access to his Deaf sister and her community:

> I have a deaf sister who motivated me into this project. I recall during our childhood, as the rest of the family enjoyed watching television programmes such as movies, music and other local entertainment, she was totally missing out and in a world of her own. It kept me thinking how l could help her. I promised that one day I would persuade television stations to air sign language programmes, even if a few, so that people who are deaf can like her could enjoy, too.[69]

After Muleka could not convince any TV stations to add sign language interpreters to its content, he decided to start his own station. By 2017, he had obtained a frequency to start his station, and the station has made a commitment to hiring disabled people, with 60% of the employees being people with disabilities, Muleka says. “Signs TV has enabled many PWDs to harness their talents by supporting their creativity and by extension reduce discrimination, social stigma and boost self-esteem,” he added.[70]

In 2021 a Kenyan journalist with albinism, Alan Herbert Onyango, pitched a five-day-a-week disability news morning show to Muleka, and he put it on the air. Onyango is passionate about the news media in Kenya doing a better job because he sees the impact of their misinformation about disability. With his diploma in journalism and media studies, he wants to change negative perceptions about disability, but he faced much discrimination as a person with albinism.[71]

> When I joined journalism school, the media was focused more on the negative side of disability, so when I asked myself what change can I bring to society. I said let me go do journalism so I can highlight on the positive side of disability. On mainstream media, nobody will risk their time to put me on prime time.[72]

He got training in broadcast journalism because he wants to be on-air to confront the stereotypes people have about albinism and other disabilities. Onyango wants to show others in Kenya that people with albinism and other disabilities can work as TV journalists. After doing an internship at Signs TV, he created the morning show that runs Monday through Friday at 6:30–9:30 a.m. The morning program covers a long list of disability-related content: general news, inclusion news, relationships and everyday information, lifestyle, food, fashion, hygiene, medical information, and Fridays are for entertainment and music, featuring DJ's and musicians with disabilities.[73]

In Indonesia, disability rights activists are using the smartphone messaging app, WhatsApp, for online organizing. Dwi Ariyani, a program officer for the Disability Rights Fund (DRF) in Indonesia, set up the WhatsApp group as a way to share information from DRF to its grantees in Indonesia, but it soon became a way to plan and organize around disability issues there. The group used it to push back against disability discrimination when two disabled people who passed the civil service exam were disqualified from civil servant jobs. Fajri Nursyamsi, who has a prosthetic limb, is a researcher with the Indonesian Center for Law and Policy Studies, which is part of the national Organizations of Persons with Disabilities Coalition in Indonesia, and he helped the country's disability organizations draft a statement to remind the government of laws that protect disabled Indonesians from workplace discrimination. Using WhatsApp, the statement was distributed to not only disabled people but also the media and other groups. WhatsApp was already being used by many people in Indonesia and so it easily became a significant tool for disability rights. Nursyamsi says, "WhatsApp is simple, and many people in Indonesia, especially the activists, use it to communicate, I think WhatsApp is also accessible for people with disabilities. It's easy to use to communicate, to discuss."[74]

Short-form videos[75] on platforms like Instagram and TikTok are also drawing disabled people. Many disabled people are using Instagram for all the same reasons as nondisabled people, capturing their daily life in images and videos, filling leisure time with a smart phone-based activities such as scrolling Instagram images, maintaining friendships, and viewing celebrity content.[76] Canadian graduate student Jennifer Mooradian studied Instagram content from young adults with Down syndrome and found a variety of positive themes in their self-representation: "Affirmative Disability Ownership, Loving Life, Living a Big Life, Driving Change, and Don't Tell Me; I'll Show You."[77] Using Critical Disability Studies and disability life writing frameworks,[78] Mooradian's research examined the content on publicly accessible Instagram accounts that had people with Down syndrome involved. She found that these young people with Down syndrome presented "themselves in ways that resist dominant disability narratives, allowing for expanded ideas of what disability is and who persons with disability are."[79] Through their Instagram presence, they were "able to frame their lived experiences in ways that highlight the benefits of life with a disability."[80] They are using Instagram to reinforce the Affirmative Model of Disability,[81] Mooradian says.[82] Instagram has become a significant location for disabled people and disability organizations; as of November 2022, the #disability hashtag had been used more 2.3 million times.[83] Instagram also provides a way for performers and models with disabilities to get jobs. Lily D. Moore, an actor and model with Down syndrome, gets many of her modeling jobs through her social media presence on Instagram and Facebook.[84]

Madeline Stuart, who is called the first supermodel with Down syndrome, found fame on Instagram, and Danish researchers Maria Bee Christensen-Strynø and Camilla Bruun Eriksen studied Stuart as a disability advocate and brand. Using a framework of affective economies that see "disability as a form of emotional currency,"[85] they say that Down syndrome becomes a brand through Stuart's use of social media like Instagram to promote her activities.

> In this framework, disability, then, is explored in itself as an empty sign to which meaning and value attach themselves through their continuous circulation. This is effectively demonstrated by paying analytical attention to Stuart's framing of the common cultural trope of weight loss as a significant transformative process, which, we argue, performs as a gateway to legitimizing and branding Down syndrome and disability as a particular capitalizable identity.[86]

They report that Stuart fits with other micro-celebrities who have acquired "Instafame" because she uses Instagram primarily to post images of herself and her successful modeling activities. But Stuart is a unique micro-celebrity because it is her physical difference as a person with Down syndrome that builds her brand as a celebrity. Stuart fits with what Tobias Raun[87] calls a subcultural micro-celebrity.[88] Christensen-Strynø and Eriksen say Stuart positions this subcultural disability identity as a brand. "This is particularly apparent in social media posts exhibiting her alliances and engagements with specific Down syndrome and disability organizations and communities," they explain.[89] They add that Stuart is able to "renegotiate and convert disability from a devalued position of embodiment within a failed economy of disability into a valuable currency of celebrated selfhood."[90] Also, Stuart's self-branding on Instagram avoids the charges of exploitation by others common in media representations of disability in the past. Christensen-Strynø and Eriksen conclude: "As the creator of a highly distinct and capitalizable brand of Down syndrome and disability, Stuart is given the possibility to exchange her accumulated positive value into goods in the form of advertisement, sponsorships, travels and a luxury lifestyle."[91] Stuart's branding through Instagram fits with how many marketers and advertisers are using the platform: through subtle and natural promotions that don't look like traditional ads so viewers of the content have a more positive response to it.[92]

Young people with disabilities also found a place to put their perspectives into the larger world on the video platform TikTok at the beginning of the Covid-19 global pandemic in 2020. Created in 2016 by the Chinese media and tech company, ByteDance, by early 2022, it had more than 1 billion users daily worldwide.[93] Like many young people, disabled youth were bored at home during the Covid-19 lockdowns and many began using the video app. The news media noticed the phenomenon and interviewed disabled people who were gaining an audience on TikTok.

> Many people attribute TikTok's seemingly overnight success to the early lockdowns of the COVID-19 pandemic — which was also why 16-year-old Isabel (@powerfullyisa)[94] turned to social media. As a public speaker, disability justice activist, and community organizer, she knew she had to find a way to continue fighting for both policy change and public awareness.[95]

Another young disabled woman, Laiken Olive, found her identity as someone with a limb difference from the experience of making TikTok videos in 2021. She told *The Washington Post* that for many years she had pretended she wasn't disabled. "'For most of my life, I ignored the fact that I was disabled. I didn't want to be disabled, so I pretended like I wasn't. But ignoring that part of myself didn't make it go away," the 20something Louisiana resident said. But Olive, who was born with a partial right arm, began to make TikTok videos "to educate people about disability and limb difference, posting to more than 28,000 followers on the TikTok account @thebionicbabe."[96],[97]

However, the ableist side of TikTok was revealed in a 2019 investigation by German journalists at Netzpolitik that was documented in the 2022 documentary, *TikTok. Boom*.[98] With its discriminatory content moderation practices leaked to the German journalists, the world began to learn that some disabled people are not welcome on TikTok. With TikTok's internal moderation guidelines in hand, Netzpolitik senior editor Chris Köver said they found in 2019 that "TikTok is specific about what it doesn't want on the platform"[99] and much of that has to do with disabled people. TikTok hides content based on:

-Physical or mental conditions
-Facial disfigurement
-Autism
-Down syndrome
-Being people with disabilities
-Being considered 'ugly'[100]

Content moderation guidelines specifically said the platform videos should avoid "disabled people or people with some facial problems such as birthmark, slight squint and etc."[101] With content moderation reminiscent of U.S. "ugly" laws,[102] TikTok hides content from some disabled people from its For You feed. TikTok is not deleting content, just hiding it so no one will see it on the platform's For You recommendation algorithm through shadowbanning.[103] TikTok claims that the shadowbanning is to prevent cyberbullying of disabled people.[104] Australian disability inclusion advocate Gina Wilson-Burns pointed out in 2022 that "fear of bullying" is often used as a scare tactic when taking away rights of disabled people.[105] Cyberbullying does exist for disabled people, but one study found that disabled students also find much support via social media platforms.[106] Slate magazine explained in 2019:

> For members of any minority group, social media provides an opportunity to connect with others with shared experiences, to find role models and content reflecting their own life that isn't represented in traditional media. Some even translate their reach into dollars. Aaron Philip, a disabled trans influencer, won modelling contracts with Sephora and Dove after going viral on Twitter, and Keah Brown landed a book deal with Simon & Schuster for her essay collection *The Pretty One* after her hashtag #disabledandcute took off. Social media suppression denies people economic, political, and cultural opportunities and, in that sense, really isn't that different from an employer not hiring a software engineer because they use a wheelchair.[107]

In terms of online videos from the disability community, creators are being empowered personally through telling their unfiltered authentic stories, and audiences are learning about disability in image and video-based public pedagogy.

Vocal difference and online content from the disability community

Since the beginning of radio and television broadcasting, those industries have defined what is a "good voice" to go out over the airwaves, often excluding voices based on gender, socioeconomic class, geography, and disability. Media and cultural studies scholar Bill Kirkpatrick says the invisibility of disabled voices and bodies in radio, in particular, is tied to the capitalistic nature of the U.S. broadcast media, which is governed by a belief that listeners only want to hear a certain kind of "voice" on the radio. But Kirkpatrick explains that with this economic argument, the broadcast industry is embracing "the ideology of 'compulsory able-bodiedness' and the rejection of disability identities."[108] Many broadcast training textbooks even equate the human voice for radio and TV with a fine musical instrument played by a broadcaster's vocal artistry. One broadcasting textbook said, "The voice is to the broadcaster as the hands are to the pianist…. the written word is transforming into compelling, meaningful information for the ear by the eloquence and style of the broadcaster."[109] Media literacy research into what journalism textbooks say about the "broadcast voice" by Elia Powers and Beth Haller "highlights the frequent cases in which speech disabilities are ignored or inadequately covered in textbook chapters that reference the public-facing, performative aspects of media careers such as speaking on air, interviewing sources, and asking questions at live events."[110]

But these journalism training textbooks ignore the many parts of journalism that are not on-air, that many interviews can be done through email, not through phones or video chats, that much new technology exists to allow nonverbal people to communicate, or just that people with speech disabilities are capable of being journalists. One example is Australian Marlena Katene, who has cerebral palsy and uses a speech device to interview her subjects. After receiving her journalism degree from Griffith University in Queensland, she began interviewing many musicians, comedians, sports figures, and actors for her YouTube channel, The AAC Journalist.[111] Katene developed a unique interviewing style to put subjects at ease with her iPad-based assisted communication:

> My interviews use a very simple formula: (1) Make the person laugh. (2) Find out quirky or unusual bits of information. (3) Find out something about the subject outside the "typical" industry they're in. [For example] I found out a certain rapper loved comic books. (4) Make your subject comfortable, then address any negative topics, but always minimize this. (5) Finish with something unique e.g. a song, joke, etc.[112]

Podcasting, YouTube, and other online audio and video production tools have allowed disabled people to bypass the traditional broadcast media in telling their stories. Open access audio and video content online allows everyone who wants to create content to do so, no matter what their voice sounds like or how they communicate. Alice Wong, who used a BiPAP mask to deliver pressurized air to her lungs, has long been an advocate of diverse voices in audio. Wong said in 2016, "On radio, I want to hear people who lisp, stutter, make noises when they talk, use computer-generated speech, communicate, enunciate, and pronounce differently."[113] She explains that when she began a community radio fellowship in 2015, she educated herself about producing stories, conducting interviews, and storytelling in general. Wong sees storytelling as a form of disability activism, and in her 2022 book, *Year of the Tiger. An Activist's Life*, she includes a section on storytelling, which includes tips on interviewing, how to get into podcasting, and the importance of diversifying voices in audio content.

Sarika Mehta, co-audio producer of Wong's Disability Visibility Podcast, said a podcast filled with disabled people's voices that may sound unique illustrates that the focus should be on storytelling, not what someone sounds like.

> I love the idea of people just having the ability to be themselves and tell these stories that are really poignant or give so much history of culture and understanding family and understanding why we are the way we are, why things are the way they are. And to that effect, because

> obviously, there's populations that cannot access something that's just that you hear, especially if you're not a native speaker of English, or if you don't hear.[114]

The Disability Visibility Podcast was intentional in its full access to everyone by providing transcripts for every episode from the beginning, Wong says. She planned and budgeted for transcripts, saying "it would be just incredibly silly and basically hypocritical if I did a podcast centering on the disability community without transcripts."[115] Disability activist Sandy Ho, who is a hard-of-hearing wheelchair user with Osteogenesis Imperfecta, was a guest on the podcast on the topic of intersectionality in 2018[116] and had always worried about how she sounded in audio content but being on the podcast empowered her:

> As someone who has always been very self-conscious about the way my voice sounds, being on the DVP podcast was really the first time that I felt confident in the way that my voice sounds and in the power that it carries. So, thank you so much, Alice, for all of the work that you've put in to making this absolute treasure happen.[117]

Ho calls the 100 episodes of the Disability Visibility Podcast an "incredible treasury of stories and conversation from disabled people."[118]

Conclusions

Disabled people's perspectives via online audio and video are broadening these newer forms of media to become powerful educational tools for both people with and without disabilities. Their content is equal to all others and possibly even more potent because of the lack of information in mass media worldwide about the disability community. This audio and video content from disabled people illustrates public pedagogy to both disabled and non-disabled audiences in multiple ways:

- It educates about disability issues.
- It educates about bodies and voices that are physically different.
- It builds comfort with physical and auditory difference.
- It strengthens the wider disability community.
- It empowers other disabled people who listen to or view the content.
- It empowers disabled creators who gain confidence from finally telling the world about their perspectives.

The disabled creators benefit because they are able to speak their truth about disability. "YouTube is a space where people with disabilities are able to present their lives and show what living with a disability is truly like, with full control over their own narratives,"[119] according to disabled YouTubers interviewed in 2020. British vlogger Hannah Witton, who makes content about sex, relationships, and disability and her stoma, says of her YouTube channel,[120] "The best thing about being a disabled creator on YouTube is definitely knowing that I'm helping people by speaking publicly about my experiences. And by showing my scar and stoma bag photos and videos online."[121] It is the best kind of public pedagogy because it comes from the authentic stories of disabled people.

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4 Performers illustrate the Affirmative Model by taking control on scripted series for web and streaming

Outspoken disabled writer and editor Lucy Gwin, who edited the U.S. disability rights publication *Mouth*, always said that the disability community had been so ignored or misrepresented in the news media that the disabled people "are just going to have to cover it our own damn selves."[1] The same holds true for the TV and film industry, which has had barriers to participation for disabled actors, disabled directors, and disabled writers for so many decades that they also have to do the work of entertainment media content featuring disability their "own damn selves."

What has been happening in television and film for decades has been a marginalization of the actual lived experiences of disabled people, so modern disabled creators are confronting this because they know the value and empowerment they feel from their disability identity. Through their innovative web series, comedy performances, Netflix shows, and more, these disabled creators are affirming their disability identity and its authentic place in many cultural contexts. They are enacting the Affirmative Model of Disability,[2] which grew out of the disability arts movement in Great Britain and is a reaction to the personal tragedy model of disability that is so embedded media and cultural content.

The Affirmative Model of Disability is an addition to the Social Model of Disability, not a replacement. It is grounded in the issue of identity from the lived experiences of disabled people. Hetherington says, "one of the main issues behind this interest in identity and in identity politics more generally has been the relationship between marginalization and a politics of resistance, and affirmative, empowering choices of identity and a politics of difference."[3] British disability and inclusion scholars John Swain and Sally French, who created the Affirmative Model of Disability, say, "by moving to a position of viewing disability as both a personal and a public or political issue, the disabled person becomes empowered to confront the cultural stereotypes, discrimination and environmental barriers that undermine quality of life and identity."[4] These cultural barriers and forms of oppression shape disabled people's identity greatly, and many times impede their participation in society.

Mark Priestly, professor of disability policy in the UK, says that because of barriers to participation, many disabled people can't find social networks and do not have the same basic rights as other adults in society.[5] Swain and

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French add that disabled people are not consulted on major topics regarding people with impairments such as genetic testing, abortion of disabled fetuses, therapies to eradicate or "cure" disabilities, or even necessary rehabilitative treatments for impairments.[6] They also explain that ableist images in mass media affect the identity of disabled people:

> The impact of media on our constructions of selves and others' identities can be profound and can lock people into ways of interacting which perpetuate the status quo and reinforce identities that individuals may not choose for themselves. As Gleeson (1999) suggests, the reductive stereotypes of disabled people – as dependent, abnormal (or freakish), helpless, or heroic and brave (in the face of tragedy) – limit the identities accessible to disabled people (including sexual, gendered and ethnic identities).[7]

Swain and French say disabled people experiences create the Affirmative Model because their disability identity and the way they live their lives are a direct affront to the personal tragedy model of disability. They list at least five ways that disabled people are affirmative:

> 1 Impairment is simply a "fact of life…"
> 2 Affirmation can be of self, "I am what I am," in direct opposition to the tragedy view of being disabled…
> 3 Affirmation can be of self in the face of the discrimination/oppression faced by disabled people, challenging social norms that set or carry expectations and also the personal devaluation when norms are not met…
> 4 Some disabled people affirm their lifestyle/quality of life as against the presumed tragedy of lack or loss of lifestyle/quality of life… Becoming impaired is not necessarily experienced as a loss or deterioration. For some it is a far-reaching life change that can be negotiated in different ways…
> 5 Disabled people collectively affirm self and disabled identity in their struggle against discrimination and oppression…[8]

Michigan State University education professor Susan Peters noted several forms of disability culture that Swain and French say inform the Affirmative Model; the one that connects well with disabled media creators and artists is the personal/aesthetic view of culture.[9] That promotes a kind of aesthetic pride among disabled people, and they use that feeling of pride to confront the tragedy model of disability and other stigmatizing cultural narratives. A disability arts organization in the UK explains:

> We are who we are as people with impairments, and might actually feel comfortable with our lives if it wasn't for all those interfering busybodies who feel that it is their responsibility to feel sorry for us, or to find

> cures for us, or to manage our lives for us, or to harry us in order to make us something we are not, i.e. ‘normal’.[10]

Swain and French explain the Affirmative Model of Disability is a way for creative disabled people to talk back to the ableist world of tragic representations of disability. The Affirmative Model of Disability is:

> Fundamentally about critique, the critique of supposed tragedy. It challenges the images and discourses of disability and impairment that convey and construct people and their lives as by necessity tragic. The affirmative model is, thus, not a model for judging disabled people’s feelings and understandings of themselves and their lifestyles/quality of life (whether or not they have recently acquired an impairment) but it is a model that stands in opposition to the dominant, ‘commonsense’ beliefs about disabled people’s feelings about themselves, their bodies and their lives.... The affirmative model says that all disabled people are subjected to a tragedy view of themselves and their lives, whether or not they feel or understand themselves to be subjected to such a view.[11]

The shows and performances from disabled actors, writers, and performers like Teal Sherer, Hannah Gadsby, and Ryan O’Connell are enacting the Affirmative Model of Disability in their media creations.

My Gimpy life

Disabled actress Teal Sherer’s YouTube series *My Gimpy Life* was ahead of its time as an online TV series. She launched her 2012 YouTube series *My Gimpy Life* before Roku’s partnership with Netflix made streaming a part of many Americans home media consumption life.[12] Sherer, who became a paraplegic from a car accident when she was 14, has been acting since she was a university undergraduate in Atlanta, Georgia. Her first “big break” was a small part in the Emmy award-winning Hollywood TV film, *Warm Springs* (2005), starring Kenneth Branagh as disabled U.S. President Franklin Delano Roosevelt (FDR) and Cynthia Nixon as Eleanor Roosevelt. The film focused on FDR’s polio diagnosis in 1921 at the age of 39 and his rehabilitation at the Warm Springs, Georgia, spa that he subsequently funded and renovated for other polio survivors. Almost as significant as kicking off Sherer’s professional acting career, she helped Branagh prepare for his role as a disabled person.[13] As an L2 paraplegic, Sherer demonstrated all the ways FDR moved as a disabled person, including donning heavy leg braces and walking in the braces while holding on to parallel bars. FDR is famous in American history for hiding his disability by using leg braces to make himself upright and then holding on to bolted-down podiums or holding on to his adult son as he walked.[14] A long-held belief was that the U.S. news media colluded with the President to hide his disability, but historian Matthew Pressman explained in

2013 that multiple news articles described FDR's life as a wheelchair user[15] and raw film footage surfaced in 2013 that showed FDR in his wheelchair on a Navy ship.[16] But images and descriptions of FDR's disability are still rare and that is why Branagh needed Sherer to demonstrate every aspect of how someone whose legs are paralyzed moved.

Sherer's character in *Warm Springs* illustrated FDR's view that polio rehabilitation at Warm Springs should not be painful but provide "the highest quality of physical therapy and social life. There were parties, poker games, movies, picnics, excursions, and visiting professional artists."[17] Sherer's character sings and dances with other disabled women in a party scene at Warm Springs. Sherer had been a professional modern dancer with the Full Radius Dance Company in Atlanta before the film. In writing about her experience on the film, Sherer gained insight into FDR's experience of disability while at the Warm Springs facility: "Warm Springs never healed FDR's legs, but it did repair his soul. Paralysis was the norm there, so he could let his guard down and be himself."[18] On the set of Warm Springs, Sherer met actress and future producer of the *The Guild* YouTube series Felicia Day, and this would be instrumental in her own journey to create *My Gimpy Life*.

Nondisabled actress Felicia Day played a character in Warm Springs, Eloise Hutchinson, who questioned why FDR had to hide his disability. Her character said, "I wish he could just wheel himself out in front of everybody" to which another character responded, "Eloise, sweetheart, he can't, it's politics."[19] Little did Day know that she would help launch a web series, *My Gimpy Life*, that was all about being out and proud with a disability. Sherer moved to Los Angeles in 2005 and Day became a close friend and mentor, she said.[20] Day wrote a script for a television comedy series called *The Guild* about online role-playing gamers similar to World of Warcraft and whose players who decide to meet in person. Day could not get a production deal but a friend suggested she produce the show herself on the newly founded online video sharing platform, YouTube, which began in 2005. *The Guild* premiered on YouTube in 2007 and had six seasons of 70 3-8-minute episodes through 2013, with a total of 300 million views.[21] Day, who played World of Warcraft constantly when she didn't have an acting job, said she was trying to show that online role-playing gamers are not young men living in their parents basement, and she wanted a comedy that didn't make fun of gamers but resonated with gamers and non-gamers as a funny show.[22] *The Guild* went on to win 14 awards for video series and streaming, with a prestigious Greenlight Award[23] at South by Southwest (SXSW) for online digital series in 2008 among them.[24] This is the model of a YouTube series that Sherer would use.

Day cast Sherer as Venom in *The Guild* for season three and Sherer says being on *The Guild* showed her how she might structure her own web series. Sherer says the Venom character "used her disability to her advantage. She was snarky, was sexual; just an all-around fun character." As an actor, she was entering a popular web series that had a large number of fans, who, through the interactive nature of YouTube, made it clear that they appreciated the authentic representation of hiring an actor who uses a wheelchair. Sherer said

> It was huge for the nondisabled audience that I was really disabled, who thought they had just put an actor in a wheelchair. People were like 'oh, that is cool, she actually uses a wheelchair.' Other disabled people started reaching out to me, saying 'that character is so cool' to see a disabled person in the show. So I was seeing all of that and that's what inspired me. I thought, I could do this. I could create my own show and people are responding to this; people are responding to me; they are responding to this character. This is something I could do.[25]

And Sherer became close with the production team members on *The Guild*, so she had people to show her the ropes of mounting a production. Sherer said she needed a script writer for her web series idea, so Day introduced her to comedy writer, Gabe Uhr. The two met and she told Uhr numerous stories about ridiculous things people say to her as a wheelchair user and lack of access she faces on a daily basis. One story in particular showed Uhr the comedy potential of *My Gimpy Life* and he jumped on board to write all ten episodes of the web series. (All the episodes run 5–10 minutes.) The story Sherer told Uhr was about a man asking her a question as she was leaving a bank parking lot, "'Hey,' he said, 'can I ask you a question? Can you have sex?' I said, 'uh, yea, yea.' He said, 'oh, cool; do you want to go out?'" That story begins season 1, episode 3, of the series, "Inspirational." That story illustrates that the comedy in *My Gimpy Life* comes from the ignorance of some nondisabled people, the ableism that pervades society, and ongoing ridiculousness of an inaccessible America.

My Gimpy Life benefited from the growing connections of like-minded folks on the social media platforms Twitter and YouTube, as well as new online crowdfunding tools for creative projects, like Kickstarter (founded in 2009). Sherer self-funded the pilot episode, which took two days to shoot at the theater company where she performed, NoHo Arts Center (it closed in 2016), and was able to use non-members of the Screen Actors Guild (SAG) because it was a new media production and could pay the actors per day. The pilot episode, "Inspirational" that became episode 3 in the first season, premiered at the ITV Festival, which screens comedy shorts and web series. Sherer said it was gratifying to see nondisabled people understand her comedy narrative. At the screening, she said, "all [those] able-bodied people who had no idea, they laughed right from the beginning. It was great."[26]

She began promoting the pilot to try to find a producer who could fund season 1 but found no producer through the traditional route of an agent shopping the pilot around in Hollywood. Then a fan of *The Guild*, Steven Dengler, saw her tweet about wanting to produce a full season of *My Gimpy Life* and reached out to her. Dengler became wealthy by founding Xe.com, an online currency exchange tool, and agreed to fund season 1. Dengler became an executive producer of *My Gimpy Life*, came to the set, and even had a cameo in one episode. Sherer says this funding came from their friendship on Twitter, his *Guild* fandom, and his desire to support a worthy web series.[27]

For the second season, Sherer and her production team did a Kickstarter crowdfunding campaign that raised $50,000 from 840+ backers.[28] Disability media studies scholar Elizabeth Ellcessor says these online funding tools allow disabled people like Teal Sherer to produce media in a way that supports her narrative about an empowered disabled woman, as well as join a community of other creative people crowdsourcing their work. Ellcessor says:

> In short, with alternate funds come additional opportunities to participate in media production and take risks that would not be supported in traditional production spaces. Projects such as *My Gimpy Life* can go beyond commercial transactions to support the formation of a persistent community that may, ultimately, produce societal changes at some level.[29]

Ellcessor says that Sherer, who strongly identifies as a proud disabled woman, used *My Gimpy Life* to harness online media to both respond to the poor presentation of disabled characters in mass media and to actively get her nondisabled audience members to understand the exclusion and inaccessibility disabled people face.[30] *My Gimpy Life* also presents narratives to which many disabled people can relate and creates what Ellcessor calls "cultural accessibility, in which media are not only technically accessible to people with disabilities, but culturally relevant to their experiences or identities, actively inclusive, and ultimately collaborative in some way."[31] As a media creator, Sherer producing *My Gimpy Life* "is a kind of activism in society."[32] The disability community embraced the show and helped promote it online, Sherer said, and she was gratified that disabled people were using the show to discuss their own experiences with exclusion and inaccessibility. She said they could begin a dialogue with nondisabled people from the show, saying: "This part where this happens to Teal; this happens to me too; let me tell you about this."[33]

The plotlines of most of the shows' episodes reflect the Affirmative Model of Disability because *My Gimpy Life* is critiquing the presumed tragedy model of disability, as well as taking on topics such as inspiration porn, ableism, patronizing behaviors toward disabled people, wheelchair access, and work relationships with ignorant nondisabled people. In Season 1, episode 3, "Inspirational"[34] (which was the original pilot episode), the Teal character must deal with false praise when she had a bad audition and a theater director calling her "inspirational." She explains how offensive it is to be seen as heroic and inspiring when she did not do good work. The episode illustrates the clear misunderstanding many nondisabled people have about people living with a disability or how they approach life. Ellcessor says "this episode critiques common understandings of disability as asexual, as well as involving an inspirational, brave, or heroic struggle against an impoverished life."[35]

In addition to a critique of the problems in an ableist world, the episodes uplift with a reflection of Sherer's actual authentic life as disabled woman and actor, which have their own power. Season 1, episode 5, "The Commercial,"[36] is about the character booking a national advertising spot, which the actual Teal Sherer did in 2008 for the Liberty Mutual Insurance Company commercial, "Election."[37] In the final episode of the series, "Viral Superstar,"[38] the Teal character gets her big break after her *Guild*-like character in a science fiction video goes viral, but she must navigate Hollywood's new and limited desire for authentic casting with the knowledge that if she gets the job in a series, other actors with disabilities won't. It is a meta episode that considers how even when Hollywood ponders authentic casting of disabled actors, it becomes tokenism because of the ableist structures so embedded in Hollywood. The 2014 episode was speaking directly to the 2013 *Ironside* TV series reboot that cast nondisabled actor Blair Underwood as the paraplegic police detective. (The series had one season of nine episodes.) Disabled actors at that time received some coverage of their call for disabled actors to play disabled characters. "Sons of Anarchy" star Kurt Yaeger, a disabled actor and pro BMX rider, said: "I want disabled characters being played by disabled people, but I also want characters that were written as able-bodied to be played by disabled actors."[39] The "Viral Superstar" episode mentions the pilot Teal Sherer did with the Farrelly Brothers, "I'm with Stupid," which she was to appear as a regular cast member in the U.S. version of the BBC comedy.[40] The half hour was not ordered for the 2007–2008 TV season by NBC.[41] This episode includes disabled actors Geri Jewell and Russell Winkelaar. (Previous episodes of *My Gimpy Life* have starred Teale Sperling, who has dwarfism, as Teal Sherer's frenemy.) Jewell, a pioneering disabled person on American TV as the first person with cerebral palsy (CP) as a regular cast member in a series, says in the episode that she has only had 20 auditions in 34 years as an actor,[42] clearly illustrating the discriminatory practice against disabled actors in Hollywood.

My Gimpy Life gave Sherer a creative outlet both to share her disability experience and to connect with the larger disability community who could access the show wherever YouTube is available. The web series views range from 26,000 to more than 114,000+[43], and the show is screened in many Disability Studies courses. Sherer would like to see Netflix pick up the show, like it did for *The Guild* web series. She says of *My Gimpy Life*:

> I wanted to share my perspective, and I knew for me it was very cathartic to share it. It made me feel less alone. But then to put it out there and seeing that people really needed it and wanted it, to see their response was like WOW.

Nanette and *Douglas*

Autistic and queer Australian comedian Hannah Gadsby burst upon the international scene with her streaming Netflix special, *Nanette*, in June 2018.[44] The Emmy award-winning Netflix version of her stage show of the same name explored her identity as a queer woman and the trauma she navigated but was also implicitly infused with her status as a neurodiverse woman. However, she decided not to have her *Nanette* show explicitly include her autism because she said just the mention of autism brings up confusion for many people, especially those who wrongly believe vaccines cause autism.[45] Gadsby discussed her 2016 autism and ADHD diagnoses as part of the narrative journey in her next show, *Douglas*[46] (2020), and in 2022, released her memoir *10 Steps to Nanette*, which details her childhood and young adult life without the diagnoses that would eventually help her clarify the way she moves through the world.[47] Gadsby says of her autism diagnosis:

> It took me a long time to get brave enough to simply share my diagnosis. My experience did not match the popular understanding of autism, and I knew I had to become an expert in neurobiology in order to untangle the myriad myths surrounding autism – just to beg permission to claim that piece of my identity.
>
> I was right to be cautious, because when I finally did start telling the world of my diagnosis, the dismissals came thick and fast. I was told I was too fat to be autistic. I was told I was too social to be autistic. I was told I was too empathic to be autistic. I was told I was too female to be autistic. I was told I wasn't autistic enough to be autistic. Nobody who refused me my diagnosis ever considered how painful it might have been for me, and it got really boring really fast.[48]

In *Nanette*, Gadsby dealt with her own traumatic life experiences (she was beaten up on the street for being queer and raped in her sleep as an agricultural worker), as well as the trauma wrought from the atmosphere of homophobia, sexism, racism, and classism in her native Tasmania in the 1980s and 1990s. As an autistic person, Gadsby began cultivating her "special interest" as a child when she found (and stole) the three art history books in her school library.[49] Her love and fascination with art is woven into both of her shows, as is the sexism and misogyny of many male artists. In *Nanette*, Gadsby critiques both the art and sexual relationships of Pablo Picasso to explore male artists' contempt for women and the continuing exploitation of women in the name of art throughout the ages. In 1927, Pablo Picasso, then 45 and living with his wife, had a sexual relationship with a 17-year-old French teen, Marie-Thérèse Walter. (The illegal affair with an underage woman is said to inspire 79 of Picasso's works.)[50] In her shows, Gadsby wields her vast art history knowledge like weapon to drill into the sordid abuse of women and poor people in the history of Western art; that narrative links to the modern-day abuse, homophobia, and sexual violence in her own story.

Gadsby's performance of comedy is a unique example of the Affirmative Model of Disability because she has come out the other side of a "tragic view" [51] of her life through her critique of the trauma she faced. She says in *Douglas* that the day of her autism diagnosis was a "very good day. I felt like I had been handed the keys to the city of me."[52] In *Douglas*, she interrogates her autism diagnosis as the central theme. It has much less discussion of her experiences of trauma and much more about how she learned to move through the world with an autistic identity. Gadsby explicitly states in *Douglas* that "this is a show about autism." She explains that many autistic people make a poor first impression so "this is a show that rewards people who persevere, who go beyond their discomfort just to see what's on the other side of the spectrum."[53]

She even structures Douglas in an "autistic way" by detailing everything she would discuss in the show at the beginning so the audience could start processing what they will hear. Autistic advocate Nera Birch says Gadsby's detailed introduction benefited her neurodiverse brain: "Getting a run-down of where the show was going and what to expect felt almost like a wonderful accommodation."[54] Birch added that with Douglas, "I have never felt this represented in entertainment before," with an additional benefit of watching it with her family who understood the real-world benefits that come from a neurodiverse brain. Birch explained: "It has taken me a long time to see my autism as a positive, at least some of the aspects. Seeing that my family views it positively as well made me feel validated."[55] She wrote, "We need more positive representation of autism in the media and this is an amazing place to start."[56]

Gadsby dismantles many myths about autistic women with upbeat humor. One reviewer said: "If *Douglas* is about anything, it is about recreating comedy as Gadsby's safe, comfortable space."[57] She discusses the sensory sensitivity of autism at the beginning by making sure there are no cell phones to cause sound or light during her performance. Gadsby drills down on the inhospitable world autistic women must live in

> She points out that expectations of women to be the emotional workhorses of social situations are so high, and autistic women learn to camouflage their symptoms to such a degree, that autism in women and girls was once thought to be an impossibility.
>
> Throughout the show she narrates her life, lived in the consequences of these misconceptions and misdiagnoses. Again and again she returns to a lament: 'This is because we live in a world where everything is named by men.'[58]

Douglas embraces the Affirmative Model of Disability by honoring the complex identity of autistic people, especially women. Gadsby told ABC News in Australia that she hopes the people who see *Douglas* begin to understand that "people on the spectrum can speak for themselves," and she wants people on the spectrum who see *Douglas* "to recognize themselves and maybe get a bit more confidence to have pride in their identity and the way that they think about the world."[59] Gadsby also connected with the U.S.-based Autistic Women and Nonbinary Network (AWN) when she performed *Douglas* in New York in 2019[60] and decided to support its work with a fundraiser linked to her joke about anti-vaccine parents who put all children at risk by not vaccinating their children because they wrongly fear vaccines cause autism. Gadsby says those parents should get a pet rock instead of having children. At her New York shows, she decorated and signed pet rocks and sold them as merchandise, with all proceeds going to AWN.[61] Sharon daVanport, the founder and executive director of AWN, said Gadsby's support was significant in highlighting the diversity of autistic people that AWN represents:

> It is impossible to underestimate how powerful it is for Hannah to thoughtfully and strategically use her platform by shining a spotlight on the abuses and violence experienced by disabled, autistic, and LGBTQIA+ people, as well as calling out everyday ableism, anti-queer and anti-trans oppression, and misogyny.[62]

Australian autistic advocate and screenwriter Clem Bastow writes in her discussion of *10 Steps to Nanette* that an autistic woman telling her own story should be praised because that is what is needed to confront the misinformation and myths about autistic women. "The notion that autistic people are best qualified to tell autistic stories is still nascent; to write about autistic literature, even as an autistic person, still necessitates the act of filtering through what has come before," Bastow writes.[63] Bastow finds many instances of "disability gain" in Gadsby's memoir; how her autistic traits led to brilliant riffs when writing the memoir. Gadsby herself discusses her selective mutism when overwhelmed:

> Because of my inability to quickly and efficiently translate what I see into an externally communicable format, I am wired to have lots of fun and adventure in my head while at the same time failing totally, utterly and miserably at life on the outside, and feeling profoundly alone.
>
> I believe that it is this whirl inside my brain that contributes to my occasional inability to speak. To be clear, I don't identify as being nonverbal, but I often lose my verbal ability. Especially if I am overwhelmed by a lot of sensory information at the same time as I am trying to identify, process and regulate emotional distress. This is what is called selective mutism, which commonly exists alongside ASD, but is not exclusive to it.[64]

But that fun and adventure in her head informs the way she can seamlessly link the images in her head to the humorous narrative she is constructing on stage. Bastow says Gadsby's memoir has a "repetition and echo" that appears to be a written form of echolalia (in which autistic people repeat the words and phrases of others in real time – intermediate echolalia – or repeat words and phrases they heard in the past – delayed echolalia).[65] Bastow writes

> In Gadsby's skilled hands, however, we see the true creativity, meaning and shifting context of echolalia in all its beauty. Nowhere is this more evident than in the chapter 'Step 3: The Formative Years', which begins with an overview of Tasmanian history subtitled 'STOP! CONTEXT TIME!', a riff on MC Hammer's 'U Can't Touch This…'
>
> The MC Hammer riff, which initially reads as a mood-lightener, soon becomes unrelenting. By the time 'STOP! GOOD NEWS TIME!' is deployed, the reader may be surprised to discover that the decriminalisation of homosexuality in Tasmania did not magically expunge the Apple Isle of the violence of homophobia. It's a remarkable rhetorical sleight of hand, but it does not exist simply to be clever: It shows the reader how Gadsby used (and uses) language and writing to navigate and survive an often cruel world.[66]

The memoir is rich with sensory detail, Bastow says; another positive consequence of the autistic brain. Gadsby's imagery of temperatures, smells, textures, and sounds also educate readers about the sensory overload that autistic people can face. Bastow writes that "in inviting the reader into this deeply felt, sensorially-focused world, Gadsby gives them the gift of empathy."[67]

Gadsby's out and proud performance of autism connects to the way the Affirmative Model of Disability is seen within the disability arts movement. British DS scholar Colin Cameron said,

> Disabled people find themselves under pressure to keep quiet about their impairments, to try and assimilate as if their impairments weren't part of who they are or are just a minor part of who they are and to regard their impairments as embarrassing hindrances to be overcome. The Affirmative Model was proposed as an idea to enable us to recall that, actually, our impairments are a core part of our being and of our experience.[68]

Gadsby is mining her neurodiverse brain for brilliant comedy and thus affirms the legitimacy of everyone's authentic autistic experiences through her own.

Special

The Netflix short-form series *Special* ran from 2019 to 2021 and told of Ryan O'Connell's story of being a gay writer with CP, who was in the closet about his disability. O'Connell has mild manifestations of his CP, a slight limp and a weak hand. After being hit by a car when he was 20, O'Connell erases his CP by telling everyone at his new online writing job that his disabilities resulted from the car accident.[69] The first season of the series explores his obvious internalized ableism, shame, and co-dependence with his overprotective mother. O'Connell is very upfront about the Ryan character in Season 1 being annoying because of ineptitude and self-loathing. The character is not meant to be inspiring at all. "I never wanted him to be this amazing virtuous figure," O'Connell says.

> As marginalised people, we're allowed to exist within very narrow slots, and I always like to challenge that. I set out to make the viewer feel annoyed at this gay guy with cerebral palsy. He doesn't have to be perfect so that you can feel good about yourself. He doesn't need to be your inspiration, honey. He can be a source of your ire.[70]

The series breaks open O'Connell's internalized ableism with sometimes cringe-inducing honesty. O'Connell himself was out as a gay man at age 17 but did not come out as disabled until 28, and his closeted true disability origin is what the series explores. By reconfiguring his disability as the more accepted result of a car accident, he thought he was avoiding heavier stigma. O'Connell's story and his Netflix series are an apt example the hierarchy of disability, which is "a social construct that makes certain kinds of disabilities more acceptable than others."[71]

When he got a book deal for *I'm Special and Other Lies We Tell Ourselves*, which would become some of the source material for the Netflix show, O'Connell began to embrace his disability because he said he needed to finally live authentically. But it is clear in his 2015 book that he still had a lot to learn about disability because he had rejected that identity for so long. He uses the R word several times in the book, illustrating his own fraught relationship with one hierarchy of disability: that physical disabilities receive less stigma than intellectual disabilities. Psychologist Dana S. Dunn says ableism manifests in nondisabled people who have "hierarchical attitudes toward disability, where, quite simply but erroneously, some disabilities (e.g., physical ones) are viewed as more acceptable than others (e.g., mental or intellectual disabilities)."[72]

The memoir was published four years before *Special*, and it illustrates O'Connell's growing acceptance of his disability identity, which would play out in the series. In the book, he has a harsh description of what he thinks being out about his disability means:

> There's a point that comes in everybody's life when you have to stop denying things that make you different and start to accept what you have been given – even if what you have been given is embarrassing, ugly, and prone to drooling on people involuntarily.[73]

O'Connell lists six things that he felt nondisabled people believed about him as a person with CP. The book's list shows a frame of the ableism he will explore in society and within himself, especially in Season 1 of *Special*:

> Number One: people will think you have more brain damage than you actually do.
>
> Number Two: people with assume you are wasted when you are stone cold sober.
>
> Number Three: people will assume that you must have just gotten into a terrible accident.
>
> Number Four: people will make jokes about cerebral palsy without knowing you actually have it.
>
> Number Five: people stare. A lot.
>
> Number Six: some people think you are in a lot of pain.[74]

Psychological theories about ableism say that people are socially and culturally conditioned to feel more affinity with people who are like them.[75] In Season 1 of *Special*, the Ryan character "passing" as nondisabled before he was hit by a car illuminates this aspect of ableism in two ways: as explanation for why the character hides his CP and in how the audience for the series could better relate to the Ryan character. In fact, nondisabled audience members could possibly see themselves behaving in a similar way of hiding a disability from birth. The Ryan character performing ableism makes his disability palatable for all the nondisabled people around him and for the Netflix audience.

Season 1 also unpacks the Ryan character's discomfort with his mostly unrecognized disability. In one scene, the Ryan character says, "I am so fucking jealous of Bob," who is a physically disabled man in a power wheelchair.[76] O'Connell says the character's internalized ableism and his privilege as a white man make him resentful and uncomfortable around people who can't hide their disabilities like he can. O'Connell uses the series to highlight his own disability denial and the damage that did to his self-esteem. O'Connell says lying about his disability was an act of self-loathing. He told himself that letting people think his disability came from being hit by a car was just a shortcut so he didn't have to explain CP, which many people do not understand.[77] O'Connell says that his not being honest about his disability also stemmed from the ableist society all around him. He told *The Guardian* in 2021 that

> Like Ryan, I have struggled with feeling like I'm enough … We were both born in an ableist hellhole, but he is more undercooked than I ever was. I never felt I had the luxury to be socially awk. My role was to disarm anyone I encountered because they were going to be so confused by …' He gestures to himself. 'This presentation. It became my job to

> put them at ease. Ryan worries about whether people around him are comfortable that he never asks, 'Am I comfortable?' That's an epiphany I've had.[78]

Although the Ryan character's internalized ableism caused him to reject dating a Deaf man in Season 1, in Season 2, he begins to be out and proud with his CP and finds kinship with the larger disability community. O'Connell says the character embracing his disabled identity in Season 2 was by design. After Season 1, he promised that the show would become "gayer and gimpier."[79] The Ryan character dates an autistic man, played by gay autistic actor Buck Andrews, who proudly shows off his neurodiversity and gayness.[80] When he meets with a group of disabled people, called The Crips, he learns the names for his experiences as a disabled man such as inspiration porn and being fetishized by a nondisabled love interest.[81] The Crips are portrayed by all disabled actors, and their leader, Natalie, is played by wheelchair user Nicole Lynn Evans, who has Osteogenesis Imperfecta.[82]

O'Connell was committed to all authentic casting in the series; in fact, he played the lead character because he wanted to make sure a nondisabled actor was not cast to play the Ryan character and becoming an actor was another way of not being embarrassed by his body.[83] As for hiring many disabled actors in Season 2, O'Connell said he was fighting back against an entertainment industry that forgets disabled people exist. "Ableism is so systemic and ingrained in our culture," O'Connell says.

> I don't think Hollywood is like Mr. Burns[84] cackling behind a desk, going 'Keep those disabled people out!' It's more that no one considers disabled people in general, which is very dark and very sad. We're usually only there for 'inspiration porn' or to serve an able-bodied character's personal growth.[85]

The disabled characters reclaim a tradition that many of them say they were excluded from, high school prom, and hold their own Crip Prom.[86] But the Ryan character is learning about disability identity and brings his nondisabled boyfriend to the prom, who talks about inspirational disabled people, assumes that all disabled people know each other, and takes over the dance circle. The Ryan character is now empowered enough to explain to his nondisabled boyfriend what he did wrong. And the Crip Prom let its nondisabled member plan the stage, which meant it had no wheelchair ramp for the wheelchair-using Prom Queen, Kit. She is played by comedian and double leg amputee Danielle Perez.[87]

Season 2 shifts in tone and embraces the Affirmative Model with its focus on disability identity and a strong narrative that has the empowered lives of the Ryan character and The Crips confront the personal tragedy model of disability. In promoting Season 2 of *Special*, Ryan O'Connell uses his platform to push back against the entertainment industry's ableist ways. He advocates for "more disabled creators," saying "we need to stop putting disabled characters in the hands of able-bodied people because that doesn't give us money or opportunities, and they don't fully get what it's like."[88] Although O'Connell hoped there would be at least three seasons of *Special*, he was able to negotiate longer episodes in Season 2 because he was told the show was canceled at the same time it was renewed for a second season. The second season had 30-minute episodes unlike the 15-minute episodes for Season 1, but O'Connell was most pleased that Netflix gave him complete creative control and agreed to the expanded format. "Creatively, they've been dream partners and [let me] make exactly the show that I wanted to make," he said. "I'd rather make two seasons of television that are exactly my vision rather than four seasons where I felt like I was making creative compromises."[89] O'Connell developed *Special* through Stage 13,[90] which Warner Bros. Digital Networks Group operated from 2015 to 2022[91] to focus on making a variety of short-form digital series.

Another positive aspect of making a deal with a streaming platform like Netflix, O'Connell said, was that he could get disability content to viewers outside the United States. But first and foremost he wants to see *Special* foster better attitudes toward disabled Americans without the condescension and stigmatization that so often permeates media content about disability. "I never wanted to identify as being a victim and to have that in the show was very important to me," O'Connell says. "I want people to stop feeling like we're something to pity, or that we need to be treated with kid gloves."[92] O'Connell continues to tell disability stories through his participation as actor, writer, and co-executive producer of the one season reboot[93] of *Queer as Folk* in 2022[94] on NBC's streaming platform, Peacock TV.[95] At the beginning of the eight-episode *Queer as Folk* series, it appears that Ryan O'Connell's character might be in a supporting role, but as the series progresses, his character and relationship becomes one of the main characters. The Peacock series also stars double leg amputee Eric Graise, who is a dancer, actor, and singer, who starred in the YouTube Red's first original series *Step Up: High Water* (2018) and in the Netflix horror-thriller *Locke and Key* (2020–2022).[96] Graise said he was thrilled to become a dancer/actor because "you don't see us reflected in Hollywood and that's where we get most of our images of people in the world." [97] In *Queer as Folk*, he says having a fellow disabled actor on set and in the writers' room is powerful: "I knew that there would be a significant bonus to having a disabled person in the [writers] room. I just didn't realize just how much of an impact it would have on me."[98] In episode 4 of *Queer as Folk*, Graise's character, Marvin, hosts an accessible sex party for disabled people, and the episode is filled with disabled people, including a cameo appearance by sex and disability podcaster and accessible sex toy creator Andrew Gurza.[99] O'Connell says disabled people's authentic experiences are "a giant well of interesting stories that we've never seen before."[100]

Conclusions

Just like the advent of YouTube helped foster a web video platform for Teal Sherer's *My Gimpy Life*, many new cable channels and streaming platforms opened up avenues for diverse TV content that allowed Hannah Gadsby and Ryan O'Connell to tell their stories. The phenomenon of "peak TV," a term coined in 2015 by an American cable TV executive to explain all the added content that came with the beginning of streaming,[101] led in 2021 to subscription streaming creating the most number of original series (922); more than cable (726), broadcast (207), or free streaming (68).[102] Researchers who studied the representation of autistic and disabled characters on TV in 2022 say that peak TV may have "contributed to an increase in shows by diverse showrunners on diverse topics and identities."[103] The researchers add:

> Notably, TV storytelling takes place over long periods of time, allowing viewers to build possibly meaningful parasocial relationships with characters that do and do not represent them, and to engage with and consume metatext and paratexts that influence understandings of authorial intent and real-world constraints on storytelling choices.[104]

Streaming platforms break the American television structure free from the control of advertisers, who want large audience numbers, and even from advertising itself.[105] This advertising-based business model for U.S. entertainment television on broadcast TV restricts the kinds of stories that can be told. But with premium subscription cable like HBO and Showtime, free-standing streaming platforms like Netflix and Hulu, and film/TV company subscription streaming like Disney+ and Paramount+, creators do not have to worry about advertisers and audience numbers. And audiences appear to be clamoring for scripted shows on platforms like Netflix, Hulu, and Prime Video, with the majority of the original content on those streaming platforms being scripted.[106]

This desire for scripted storytelling comes from what film and media culture researcher Jason Mittell calls a new kind of narrative complexity in television storytelling. He argues in his 2015 book, *Complex TV: The Poetics of Contemporary Television Storytelling*,[107] that streaming ushered in a style of television that focuses on serialization that engages viewers in such a way that they have to keep watching to get the full story, which is unlike the TV structure for dramas and sitcoms in which each episode has a story that wraps up at the end. Complex TV storytelling creates episodic television that must be watched in sequence to fully understand, e.g., dramas like *Breaking Bad* or *Game of Thrones*, and it has the potential to create an obsessive fanbase. Mittell says it began with shows like *The X Files* (1993–2003, 2016, 2018).[108] This structure of television became an excellent fit for video streaming platforms and for what DVD sets of TV series and streaming would create, binge-watching.[109]

With a focus on storytelling and original content instead of advertising, a creator like Ryan O'Connell could develop disability content at Warner Bros. Stage 13, the original digital content studio of Warner Bros. Diana Mogollón, the Senior Vice President and General Manager of Stage 13, says the studio

> Curate[s] multicultural, intentional, and intersectional storytelling at all levels. This means actively shape-shifting alternative formats, genres, IP, business & production models to maximize storytelling opportunities.... We encourage creators to unapologetically be themselves, and this is reflected in our storytelling and production approach.[110]

Special is specifically about a gay disabled man's experience, and O'Connell said he needed a platform that would not be upset by showing gay men having sex.

Another benefit of getting the deal with Netflix was its commitment to marketing *Special*, and O'Connell says Netflix were "huge champions of this show."[111] He added that he worked "with a delightful group of gay men and women who just love the show and want more diverse voices on TV."[112] Unlike broadcast television advertisers who may not want to put their ads in a show because of the content, Netflix can air whatever shows it wants. O'Connell said his experience with Netflix: "They're taking chances. Their notes were never mandates, ever, ever, ever. They're just suggestions, and they were so collaborative."[113]

Finally, streaming platforms can curate disability content so their subscribers can more easily find shows like *Special* on Netflix or *Ramy* (2019–2020), which co-stars disabled actor Steve Way[114], on Hulu. Hulu launched its disability collection in 2020 in conjunction with the 30th anniversary of the Americans with Disabilities Act. Josie Brown, Director of Brand Marketing at Hulu, said:

> To help play a small role in providing people with disabilities a voice and to shine a spotlight on the 30th anniversary of the Americans with Disabilities Act this year, we thought it was important to create a content collection dedicated to disability representation.

Hulu as a company has Employee Resource Groups (ERG), which advise on Hulu's diversity and inclusion strategies.[115] ERG groups focus on LGBTQ+, the Black community, women, and for the disability community, the ERG is called a11y. The disabled members of a11y made sure Hulu's disability collection focused on authentic disability representation, which is about two-thirds of the collection. Brown added:

> They offered important insights, helped us build the 'Disability Representation' collection, provided guidance on our language and messaging, and served as a resource to review the accessibility of our marketing

> assets. To ensure authenticity, it's crucial that we work hand in hand with members of the diverse community that we are celebrating,[116]

Hulu also continues to work on the accessibility of its content; in 2020, it had 104 titles with audio description (AD).[117]

Netflix created its disability collection a bit later, in May 2022 in recognition of Global Accessibility Awareness Day. The streaming service was primarily highlighting its enhanced accessibility features internationally, like closed captioning and AD.[118] It also shared the story of its Director of Product Accessibility Heather Dowdy, whose first language is American Sign Language because she is a Child of Deaf Adults (CODA). She says she is a proud member of the U.S. Black Deaf community and has made it her mission to make a more accessible Netflix.[119] In 2022, it expanded it supported languages of ADs and subtitles for the deaf and hard-of-hearing (SDH) to more than 40 languages. In addition, Netflix better identifies its accessibility features through badges on the web and iOS.[120]

> At Netflix, we're also telling more stories by and with people with disabilities in mainstream culture. That's why we've launched our first-ever collection, titled "Celebrating Disability with Dimension," featuring over 50 shows and films with characters or stories about people living with disabilities. With over 1 billion people living with disabilities globally, the opportunity to tell more inclusive stories and bond within our communities over storytelling is tremendous. We will also be hosting Accessibility Screenings in select countries globally to bring our AD and SDH features to life outside of the living room and discuss ways to make entertainment more accessible.[121]

In addition to the streaming platforms having disability collections, the ease of searching for disability content allows for writers to curate their own lists of recommended disability shows, films, and series. In the early days of the Covid-19 pandemic, a writer with the U.S. disability non-profit Easter Seals New Jersey listed streaming content featuring people with disabilities on Hulu, Netflix, and Amazon Prime. She encouraged everyone quarantined to explore authentic disability representation, saying "not only do we need to see more stories of individuals who have disabilities, we need to see more stories FROM individuals with disabilities."[122] The list of TV/streaming shows and documentaries only includes content with actual disabled people in it. She says her listing of shows are

> Examples of stories told by the people who can tell them best. Whether documented, or scripted, the stories of those with disabilities matter, and the way they are presented on our screens matter just as much. We must demand more from the content we watch. There are disability stories to be told and plenty of individuals with those disabilities that

> can tell the stories best. We cannot settle for presence, we must demand authenticity.[123]

Ryan O'Connell explains that the capitalistic structure of the American entertainment industry has blocked most disabled people from participation in that industry. "Real power can only be accrued through opportunities, and you need to be given the keys to tell your own story," he reminds everyone.[124] As O'Connell bluntly reminded the world when he was interviewed in *The New York Times*: "Why, in this woke-ass culture that we live in, where so much attention is given to marginalized populations, do people with disabilities still largely go ignored?"[125]

Notes

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5 Disability as superpower

Comics, graphic novels, and music

In January 2022, Apple TV+ launched a new animated series for children, *El Deafo*, which is based on Deaf author/artist Cece Bell's 2014 children's graphic-novel memoir of the same name. Both follow child Cece's journey after meningitis caused her deafness as a four-year-old. As she enters elementary school, she creates an alternate superhero persona, El Deafo, to cope with her new deaf person identity with a prominent hearing aid, The Phonic Ear, strapped to her chest.[1] The show is a clear descendent of the comics, cartoons, and graphic novels created by Deaf or disabled people since the 1980s.

This chapter also purposefully combines comics with disabled musicians because there is overlap in some of these disabled creators' lives, as well as theoretical linkages. Krip Hop Nation Founder Leroy Moore says he saw the power of comic art and graphic novels when he read the graphic-novel memoir of disabled rapper MF Grimm in 2007, which led to him writing the *Krip Hop: Graphic Novel* in 2019.[2] Although well-known as a space for Black disabled hip-hop artists, the Krip Hop Nation defines itself as a global group of artists with disabilities, including not only musicians but visual artists as well. In fact, the Krip Hop Nation tagline is "more than just music."[3]

Theoretically, comics, graphic-novel memoirs, and music from disabled people are what Disability Studies scholars like Margaret Price[4] and G. Thomas Couser call counter-diagnosis and counter-discourse that challenges the common cultural tropes about disability/mental illness/chronic illnesses, which are typically negative stereotypes or medicalized representations that do not account for the multifaceted lived experiences of disabled people. Disability Studies and Life Writing scholar Couser in his book *Recovering Bodies, Illness, Disability, and Life Writing* says that people with disabilities/chronic illnesses are rebelling against the dominant discourse "to challenge the idea that marginalized people are necessarily pathetic victims."[5] They are actively asserting they are not to be passively objectified, and they are fighting back against their erasure in society, Couser says. Instead, "one of the most powerful motives in contemporary narratives of illness and disability

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is the impulse to invalidate the dominant cultural tropes of 'invalidity' – to demystify and destigmatize various conditions."[6] He adds:

> Narratives of illness and disability are a medium in which the writers probe and give expression to the complex dialectic of mind, body, and culture. At best, then, illness narratives remind us of what we share with each other – living in and as bodies, with all the pleasure and pain, joy and frustration, that that entails.[7]

Sathyaraj Venkatesan and Sweetha Saji call these creative works (in their study of graphic memoirs by two women with mental illnesses) sites of "productive resistance" that reconfigure the representations of disabilities through both words and images.[8]

> Through such stylistic drawing techniques, [graphic-novel] memoirists not only make visible their [mental] illness conditions, but also take control of the condition's aesthetics. An artist's experiential domain allows her not only to redefine her own self-perception engendered by the illness but also to expose the mainstream/dominant cultural scripts on illness that border on stigma and exclusion.[9]

These visual-textual representations of disability/chronic illnesses also resonate with many audience members who share those disabilities/chronic illnesses. Thembeck says through this mutual identification from both artist and audience members, they all "become active agents in their personal, political, and cultural negotiations of health and disease."[10] In their analysis of graphic novel memoirs of Ellen Forney's *Marbles: Mania, Depression, Michelangelo and Me*[11] and Rachel Lindsay's *Rx: A Graphic Memoir*,[12] which both describe the author/artists' bipolar disorder, Venkatesan and Saji add that

> Utilizing tools of counter-diagnosis like verbo-visual metaphors, their memoirs evolve as a counter-space where subjective and emotional truths gather momentum over the biomedical and popular discourses of mastery. Comics also provide a safe space for author and reader alike to examine this oscillation between standardized representative modes and identity constructions through cross-discursive patterns that verbo-visual metaphors entail. By including varied embodiments of illness conditions through such multiple modes of representation, these memoirs pluralize the self-representation of illness, countering the singular view of normalcy that relies on monotony, and thus they humanize mental illness.[13]

The modern-day use of comics to discuss the actual lived experience of disability began in the 1980s, when two disabled cartoonists, Dave Lupton in the UK and John Callahan in the United States, succeeded in getting their irreverent cartoons into the print media of both countries. Lupton, whose cartooning identity is Crippen,[14] had drawn as a child to deal with abuse, and then in 1980s, he was in a car accident and used a wheelchair for a time. Upset by the way he was treated as a wheelchair user, he began drawing again and met disability activists. "I began to meet disabled people who were politically enlightened and aware of the social model of disability," Lupton said.

> My mind opened up to all these possibilities for cartoons about barriers and oppression. Looking back, I realise I'd always been a disabled person because of impairment and mental health issues following childhood trauma – but using a wheelchair focused things.[15]

Initially, Crippen cartoons had two audiences, nondisabled people and disabled advocates, but it soon became clear that the nondisabled people and their organizations wanted "sanitized" cartoons, which Lupton soon quit providing. He focused on disability rights cartoons that are in line with the social model and has been publishing his cartoons via the UK's platform for Disability Arts Online for more than 30 years. Lupton says he appreciates his connections with disabled artists, and he takes a collaborative approach with disabled audiences, soliciting feedback on Facebook and using it to "develop and critique new cartoons…without being censored." With online discussion Lupton says, "I'm gathering suggestions, creating and sharing ideas with other disabled people."[16]

In the USA, one of the earliest American disabled cartoonists to take on disability topics, John Callahan, wanted to be a Bob Dylan-like singer/songwriter. Instead, he became a kind of outrageous spokesman for disability humor in 1989 when his autobiography *Don't Worry, He Won't Get Far on Foot* became a commercial and critical success.[17] He had been producing many cartoons for major U.S. magazines in the 1980s, but his autobiography's success gave him a national platform in those pre-internet days. At the age of 21, Callahan became a quadriplegic from a 1972 car crash, but he did not get serious about his cartooning until he got sober, having been drinking since he was 12. He said he began focusing on cartooning as a career in 1981[18] and first published in *The Willamette Week*, an alternative weekly publication in Portland, Oregon, which had help launch the cartooning career of *The Simpsons* creator Matt Groening.[19] His cartoons stirred up so much controversy from what nondisabled people saw as being "politically incorrect," that *The New York Times* attempted to explain Callahan in a 1992 Sunday magazine article called "Defiantly Incorrect." His rise in notoriety can also be tied to the fact that the United States had finally passed a comprehensive federal disability rights law, the Americans with Disabilities Act, in 1990. *The New York Times* wrote that "for all the liberating intents of the new law, Callahan would add another dimension, one that defies legislation: the freedom of the disabled to laugh at themselves."[20] Between 1990 and 2010 [the year of his death], he published eight cartoon books, a children's book, and one "quasi memoir" in which he published what he called "the best (or the worst) letters to the editor" about his controversial cartoons, adding "no cartoonist on earth had received more disgruntled letters than I."[21]

Callahan knew he was speaking (and drawing) to confront ableism and turn disability stereotypes on their head. "I'm sick and tired of people who presume to speak for the disabled," Callahan said in 1992. "The question of what is off-limits should not be defined by some special interest group. The audience, the readers, should decide," especially disabled audiences.

> My only compass for whether I've gone too far is the reaction I get from people in wheelchairs, or with hooks for hands. Like me, they are fed up with people who presume to speak for the disabled. All the pity and patronizing. That's what is truly detestable. [22]

The Miami Herald, which carried Callahan's work in its Sunday magazine in the 1990s, reported:

> When we get complaints about his handling of the subject of disability, they are almost always from people without disabilities themselves. And whenever we hear from the physically disabled, individually and through organizations promoting their interests, what we hear is loud and enthusiastic applause.[23]

Callahan saw himself as a kind of free speech warrior fighting against people who were trying to limit humor in the name of political correctness. One disability activist said it was nondisabled people who found Callahan's work problematic.[24] In 1991, he won the Freedom of Expression Award from the American Civil Liberties Union (ACLU) of Oregon, which confirmed his place as someone taking on those who would try to curb his freedom of speech. Callahan said he was proud of his uniqueness in cartoon themes

> I've never been the kind of cartoonist who is interested in cartoon themes like pets, dieting, the boss at work, etc. Life to me is major league, and I'm drawn to the aspects of it that typify the struggle: death, disease, insanity, feminism, tragedy, disability, etc. Though my work also includes themes of sweetness and frivolity, I'm afraid I've been cruelly and unjustly typecast as sick and twisted. Let it be known that I have never once answered any of the 'lively' letters aimed at me. Except once, when I could no longer abide the criticism that 'Mr. Callahan could not possibly understand the struggle of someone with a spinal injury.'[25]

British disability language scholar Jenny Corbett said Callahan's style of disability humor is not the problem, it's the solution. "This exploration of bad taste in disability imagery could be seen as the antidote to tragic imagery, mocking and teasing, instead of displaying misery."[26] Similarly, writer Sharon Wachsler, who has multiple chemical sensitivity, Lyme disease, and myalgic encephalomyelitis/CFS, created Sick Humor postcards to reflect on the reality of her disabilities: "As I was confronted with the daily frustrations, indignities, and peculiarities of life with chronic illness, I started drawing cartoons that depicted my experiences – transforming my anger into comedy."[27]

In 2000, Callahan made the transition to children's television with the Nickelodeon television show, *Pelswick*, saying he felt that kids would respond to his honest style of cartooning and his irreverence.[28] The main character is a wheelchair-using middle-schooler, Pelswick Eggert, who has fun and friends and works out problems with a guardian angel, but rarely are his problems about using a wheelchair. One reviewer said, *Pelswick* "sees things the way they are. He's fearless, extremely funny and doesn't define himself with this disability."[29] The show covered topics that would try to engage kids: censorship, the rights of disabled people, boy bands, the Pokémon trading card craze, Pro wrestling, and reality TV.

Nickelodeon said that it added the show in an effort to diversify children's programming; *Pelswick* became the first physically disabled cartoon character with his own TV series.[30]. A Nickelodeon vice president said, "*Pelswick* is part of Nickelodeon's goal of reaching out to all young people."[31] *Pelswick* was also the first disabled cartoon character written by a disabled cartoonist and Nickelodeon said that authenticity mattered to the network: "'I 'think (Callahan's experience) gives it authenticity and integrity that allows him to go boldly where he wants to go," said Cyma Zarghami, Nickelodeon's Executive vice president, adding that she would not have felt comfortable airing humor about a disabled character unless its creator was disabled.[32]

Pelswick was embraced by the disability community as well. The late arts critic and disabled actor Neil Marcus said that *Pelswick* had

> Major disability cool…He's a regular kid, with what I thought were very well placed or balanced character traits. For example, disability seems to be the least of his problems or concerns. Should it be his main concern? No! After all, this is the new millennium and *Pelswick* is interested in… living.[33]

The disability rights online publication, The *Ragged Edge*, said, "*Pelswick* totally gets it right about cripdom. Who says you can't laugh at quads? Callahan shows how to do it the right way."[34] Although it only lasted two seasons of 26 episodes, *Pelswick* was aired on Canadian TV, UK's Channel 4, and in fall 2002, it became part of American TV's CBS Saturday morning line-up. While Callahan's children's cartoon show was embraced, his adult cartoon show, *John Callahan's Quads*, was back to his irreverent themes about disability and could not find an American network to air it, so its two seasons (2001–2002) found a home on Teletoon on Canadian TV.[35] *Pelswick* as a character set the stage for more disabled characters in children's animated shows. Characters like *Punky* on RTE in Ireland, about a six-year-old girl with Down syndrome, was an animated show for preschool children that began in 2010. It focused on the Punky character, who helps her family and has adventures. RTE said Punky was the first cartoon series in the world to have a main character with Down syndrome. The series aired 20 episodes in 2010–2011.[36]

Another memorable disabled character in televised comic form is Toph Beifong, who is a blind female character on *Avatar: The Last Airbender*. It is unclear why a blind character appears, but she is one of the most popular ones in that universe. Born blind, Toph's story is one of empowerment after being underestimated and considered fragile by her overprotective parents, who even kept her existence a secret from the world. When she meets other blind beings, Badgermoles, Toph feels connected to them and they teach her earthbending, which allows her to navigate and know about objects in the world using vibrations. She becomes an earthbending champion known as The Blind Bandit. The show had three seasons of 61 episodes on the Nickelodeon network (2005–2008) but found a rebirth of popularity on the streaming service Netflix for a new generation of young people and a revisit from many college-age students who had access to their beloved childhood show. When it was released on Netflix in May 2020, it quickly became the most watched show on Netflix.[37] A student newspaper columnist for Ithica College in New York, Avery Alexander, called *Avatar: The Last Airbender* a pioneer of good disability representation. She said when she watched her favorite childhood series again in 2020,

> I picked up on just how ahead of its time the show was in its portrayal of characters with disabilities. Instead of drawing attention to its characters with disabilities and othering them from the rest of the world because of how different they are, *Avatar: The Last Airbender* integrates their contributions seamlessly. This natural inclusion is a major step away from how we usually see these characters in modern media.[38]

As a young adult now, Alexander seems to know much more about how disabled people interact with the world so the Toph character seems more ground-breaking. She writes: "The way she [Toph] uses the vibrations is reminiscent of the way blind people in real life use tools like canes to feel the texture of the ground or to sense objects in their surroundings. She does not miraculously have the ability to 'see,' and the show makes that quite clear."[39] To back up this statement, Alexander links to an article that interviews noted blind Disability Studies scholar, Georgina Kleege, about a white cane as technology for blind travelers.[40] Alexander argues that the Toph character is not a "supercrip" but just a competent young person: "Toph is powerful and excellent at what she does, she is not strong despite her disability. She is just strong."[41] Although Toph was not created by disabled people, its new Netflix availability led to many Disability Studies students citing her as a memorable disabled character[42] and disabled bloggers discussing the character.

Productive resistance from graphic novels/memoirs by disabled people

Venkatesan and Saji frame the creative content of graphic memoirs by two women with mental illnesses as "productive resistance" to inauthentic mainstream representations of their mental health disabilities.[43] But "productive resistance" can be applied to all forms of graphic-novel content from disabled people, as well as music from the disability community. Shoshana Magnet and Amanda Watson explain in their chapter in *Disability Media Studies* that comics, graphic novels, and graphic memoirs by disabled people serve to disrupt the many ableist narratives in the medical fields as well as in media content.

> The possibility of interrupting contemporary ableist depictions of disability through comics – especially in the genre of visual autobiography in which people with disabilities write about themselves and their lives in pictorial form – remains a helpful corrective to mainstream and commercial representations.[44]

Comic and graphics content with its more visual approach allows for audiences to truly see the embodiment of disabled people in their everyday lives, even if the writer/artists have a hidden disability. These graphic memoirs depict the ableism at most levels of society.

For example, John Callahan's single-panel cartoon, "Standing Room Only," shows a spinal cord injury center with a notice on the door saying, "Standing Room Only." The cartoon appeared in 1993 in *The Miami Herald,* whose editor said that the newspaper's disabled readers enjoyed Callahan's cartoon because they understood that Callahan is critiquing the barriers wheelchair users face:

> The reason why our disabled readers love Callahan is that they don't misread him. Is it a joke at the expense of people in wheelchairs? Hardly. Here's a clinic specifically designed for the disabled – presumably run by able-bodied doctors who don't understand the needs of the people they serve. Standing Room Only. The joke's on those of us who can stand.[45]

Callahan's cartoons pointedly called out society for its ableist ways. Callahan's humor in his cartoons was a form of productive resistance by countering the negative stereotypes of disabled people and challenging the beliefs of nondisabled people who felt superiority over disabled people and their bodies.

In a similar fashion, graphic memoirs by Allie Brosh, *Hyperbole and a Half*,[46] and Miriam Engelberg, *Cancer Made Me a Shallower Person*,[47] show the onslaught of everyday ableism and microaggressions they face. Magnet and Watson's analysis of these two graphic memoirs explain that graphic memoirs can also show the trauma that ableism causes for disabled people. Brosh's graphic memoir "pictures the emotional consequences of invasive ableist questions."[48] They add that graphic memoirs

> Are a form of media that engage with disability studies by picturing some of the harms of systemic forms of ableism and leaving the possibility for us to think about how to imagine alternative responses to chronic pain, depression, and life-altering diagnoses.[49]

Several scholars have analyzed Ellen Forney's graphic memoir *Marbles: Mania, Depression, Michelangelo, and Me*, which explores her bipolar diagnosis and how she integrates the new information about her mental illness into her work as an artist. Venkatesan and Saji explain that *Marbles* illustrates Margaret Price's notion of counter-diagnosis,[50] in which people with chronic illnesses/disabilities write about their lives in ways that challenge stigmatized views of them. Venkatesan and Saji say:

> In *Marbles*, Forney delineates her struggle with fluctuating moods that are characteristic of bipolar disorder and her meditations on artistic creativity and on having a diseased identity. Forney, in her quest for long-term mental stability, attempts to discover a balance of medication and lifestyle therapies, as bipolar disorder defies an easy treatment. Deploying visual metaphors and also through deftly manipulating space/page layout, Forney chronicles a range of psychic experiences from depression to manic excitement. Distancing herself from the existing discourse of mental illness as untranslatable and unavailable for representation, in *Marbles* she actualizes the experience through both conventional and creative tropes.[51]

Using her lived experiences of bipolar disorder, Forney's *Marbles* pushes back against negative and exclusionary representations of a mental illness. Venkatesan and Saji explain that these negative stereotypes of mental illness in society also influence clinical practices of healthcare workers by "disregarding patients' individuality or the distinct nature of [mental] illness,"[52] adding that "in practical terms, such subversions and revisions grafted into the discourse on mental illness via graphic memoirs expose the depersonalizing episodes rampant within clinical settings."[53] Other scholars say that Forney's *Marbles* also allows her to negotiate her past identities with her new diagnosis. Kristen Gay explains in *Disability in Comic Books and Graphic*

Narratives that "despite the complexity of Forney's identities, and the difficulties she has making peace with them, she ultimately finds a way to view bipolar disorder as part of her identity – not the sum of it."[54] The new diagnosis does not define Forney, but the DSM definition allows her to reformulate how she characterizes all parts of her post-diagnosis identity. Graphic novel/autobiography scholar Jodi Cressman says Forney's *Marbles* presents a balanced approach to merging a disability or chronic illness into one's identity:

> Forney's focus on balance rather than cure presents a disability narrative that clearly represents illness as an important and abiding aspect of human experience. To live with disability is to see it as company and counterbalance – a distinct aspect of one's identity, but not its totality.[55]

Another significant contribution of graphic memoirs crafting a narrative of identity exploration is Cece Bell's *El Deafo* about her new life as a deaf child after becoming deaf at age four. Part of its power lies in its youth audience, who get to learn about a fellow child's life acquiring deafness. Bell uses bunny characters to represent the characters and she says that was intentional

> As the only deaf kid in my elementary school, I felt very different and isolated from everyone else. Having to wear my awkward hearing aid intensified that feeling. To metaphorically show the magnitude of this, I made all the characters bunnies. What are bunnies known for? Big ears; excellent hearing. In the book, my bunny ears are just as big as everyone else's — but they don't work the same. Plus, I've got those funny-looking cords. Embarrassing! It wasn't easy being a broken-eared bunny. And thankfully, I don't feel like that now.[56]

Teachers in K-12 and higher education are using *El Deafo* to help their students understand disability or deaf identity and how similar all humans' life experiences can be. Sara Kersten, who is deaf and a professor of literacy studies at the University of Nevada-Reno, says, "I have never read a book that just so perfectly encapsulated my own experiences. I'd never seen myself so clearly in a book."[57] Kersten also conducted research about how *El Deafo* could confront university students' misinformation about deafness. She found that the book assisted the students in understanding the common experiences that all children experience, whether they are deaf, hearing, disabled, or nondisabled. When the Cece character has her feelings hurt by someone she thought was a friend, Kersten says students see

> The universal frustrations of people who have been hurt by the callous words of others and allow readers an additional means of connection to the emotions Cece felt. Making friends, having a crush, and feeling lonely are common experiences to everyone, and these universal emotions push against the idea that Cece is defined by her disability.[58]

In addition, the graphic novel format allows students to better connect with Cece's experiences because of the added power of visuals for readers. Kersten writes that *El Deafo* links easily to the social model of disability, while still acknowledging Cece's hearing loss. The book makes clear that it is lack of closed captions on the TV shows she wants to watch that "disable" Cece, not her deafness. Kersten explains that *El Deafo* has more power as a graphic novel:

> Beyond being a piece of literature that is a window into a new, potentially different, experience, its complex text and graphic elements, engage the reader. As a result, *El Deafo*, being a piece of literature, a memoir, and a graphic novel begins to allow for conversations beyond the facts of a disability. The layers of narrative, illustrations, and other features of graphic novels guide readers through complex questions regarding the hidden nature and emotions someone with a disability may experience.[59]

Girlhood studies scholars Wendy Smith-D'Arrezo and Janine Holc say that *El Deafo* creates a new perspective within children's literature about disability; it allows for a questioning of "normative able-bodiness."[60] Cece's deafness and large Phonic Ear hearing aids are never erased but become part of a superhero narrative that Bell (and her readers) understand to be a child's reframing of the concept of "deaf gain."[61] In an important scene in the graphic novel (and now 3-episode Apple+ TV show), Cece discovers that when her teacher is wearing her microphone so Cece can hear her through the Phonic Ear, she can also hear the teacher anywhere in the school. When the boy she likes discovers this, the whole class enlists Cece to tell them when the teacher is returning and they will stop goofing off and quickly look studious again. In a scatological twist that delights children, Cece can also hear when the teacher is peeing in the toilet.[62] The power of the Phonic Ear to give Cece unique powers leads her to fanaticize about the El Deafo superhero, who she says who is "just like Bruce Wayne using all that crazy technology to turn himself into Batman on TV."[63] Lauranne Poharec writes that Cece

> Regains a sense of self-worth and agency by owning her disability and assigning a new (personal) symbolic meaning to her hearing aid. Seeing it as a supersonic device that allows her to help people around her, she designs her superheroic alter ego, "El Deafo," and reframes her disability by packaging it as an asset instead of an impediment.[64]

But El Deafo is not a "Supercrip." Poharec explains that Bell does not create El Deafo to inspire anyone

> But to invite them to experience her world. She asks us to redefine what we understand by disability, encouraging a new conceptualization of

> the self and humanity, one that is posthuman and inhabits a liminal space that dismantles the boundaries between human and animal, human and machine, abled and disabled bodies.[65]

Cece Bell, like many disabled people who make art/write memoirs in the graphic novel format, is what Poharec calls a "creative activist,"[66] who reveals the lived disability experience while simultaneously critiquing the ableism and barriers to full inclusion that disabled people face. Autobiography specialist Leah White referred to these as "autobiographical manifestos" when discussing mental illness memoirs. White says, "The autobiographical manifesto can function as an important tool of discursive resistance.... We cannot deny the unique power autobiography can provide us as a means through which to explore and articulate the self."[67] The term could apply to all graphic novel memoirs from disabled people because their content focuses not on "cure" but on the discrimination and ableism they face.[68] These graphic-novel memoirs are a way for disabled people to bear witness to the barriers they face.

French writer and blogger Julie Dachez, who is now a social psychologist, told the story of her autism diagnosis in graphic novel form in *Invisible Differences* (*La différence invisible* published in French in 2016 and in English in 2020). The graphic novel confronts France's wrong belief that mothers cause autism in their children and that psychoanalysis can "treat" autism.[69] Dachez's story is illustrated by Mademoiselle Caroline and has characters rather than a memoir structure. The book also serves as a guide on how to reframe disability in one's own mind. Near the end of the book, the main character Marguerite is depicted as Wonder Woman flying through the air with text that says, "Concretely speaking, the challenges she faces remain the same, but her perception of them has changed: Not only has she learned to know and love herself, but she has also developed critical opinions on the way difference is pathologized."[70] The book helps its readers know about neurodiversity – their own and others, which links to the idea of an autobiographical manifesto because she is reacting to France's backward notions about autism. And autistic people feel seen. Christopher Chiu-Tabet, who writes about comics at Multiversity Comics, said in his 2021 review of *Invisible Differences* that "I am almost 30, have Asperger's syndrome, and this is the first time I have read a comic book with an autistic protagonist."[71]

Even graphic novels that are not memoirs can help readers understand the lived experience of disability when they have a disabled writer involved. The disabled character from the DC Comics Batman franchise is Barbara Gordon (Batgirl/Oracle). Shot by The Joker in Alan Moore's *Batman: The Killing Joke* in 1988,[72] she becomes a paraplegic wheelchair user who calls herself Oracle in some future iterations of the comic. She uses her information sciences/librarian background to help fight crime through leveraging information technology, gathering intelligence, and even some computer hacking.

Her true disability story came in 2020 when the Dutch autistic YA writer Marieke Nijkamp wrote *The Oracle Code,*[73] a YA graphic novel in collaboration with illustrator Manuel Preitano. The novel follows teenaged Barbara Gordon as she goes into the Arkham Center for Independence for rehabilitation after she sustains the spinal cord injury. The Barbara Gordon character goes through a common rehab emotional transition from nondisabled person to wheelchair user. And mysteries at the rehab center crop up, and she sees that her disability will not prevent her from solving these mysteries or anything she may tackle in the future.[74] Even though Nijkamp has autism, not a spinal cord injury, she says being autistic informs her writing and her activism in a positive way. "I know what it is to be marginalized," she says.

> I know what it is to be denied agency because my voice is seen as less important than that of a neurotypical person. I know what it's like to fight for the right to be as well as the right to be myself.[75]

Nijkamp wanted to tell the story of a young disabled woman learning to accept her new circumstances:

> She goes to the Arkham Center for Independence to adjust to life in her wheelchair. And as a result of that, she's fighting to figure out who she is anymore. It isn't until she finds hacks and puzzles and creepy mysteries in the Center around her that she begins to realize she's still Babs. How she is has changed, but who she is hasn't.[76]

In working with the illustrator of the graphic novel, she was very careful to make sure assistive devices were depicted correctly:

> When it came to things like making sure he got the wheelchairs and various assistive devices etc. right, we just discussed it openly. I sent him a whole bunch of photos and videos and he took *such* care with it![77]

Nijkamp also made sure Barbara Gordon had disabled friends and mentors in the story "to keep her from falling and to teach her joy."[78] *The Oracle Code* confronts society's belief, pushed by the medical world, that disabled people should be cured, "fixed," or hidden away from nondisabled people. This can cause actual harm, Nijkamp says.

> At best that turns into the idea that we're not as valuable as abled people, at worst that we're a threat to humanity and a drain on resources. Historically, that perceived lack of humanity or human value has been used to argue in favor of eugenics, institutionalization, inequality, denying us our agency. And on an individual level too, being told that you're broken is pervasive. It stands in the way of access. It stands in the way of acceptance.[79]

Importantly, even the publishing world grasped this theme in *The Oracle Code*. A *Publishers Weekly* review said that "Nijkamp repeatedly explores the idea that people with disabilities needn't be 'fixed,' along the way considering how stories can be used to reveal hard-to-communicate truths."[80] Marieke Nijkamp's background with stories about disabled teens made her the perfect person to guide the graphic novel story of teenaged Barbara Gordon; in 2018, she edited a collection of fictional stories about disabled teens called *Unbroken;* all written by disabled people.[81]

Comics and music intersect at Krip Hop Nation

As mentioned, Krip Hop Nation founder Leroy Moore had an epiphany when he read the 2007 graphic memoir, *Sentences*, from disabled rapper MF Grimm (Percy Carey), and it led him to an understanding of the intersecting power of comics and hip-hop music. *Sentences: The Life of MF Grimm*, published by DC comics,[82] tells not only Carey's life story but also the beginnings of rap music itself. And like other autobiographical manifestos before it, *Sentences* details how Black disabled men are treated in U.S. society, especially by police. The book starkly shows his 45 days in jail without his wheelchair:

> I literally had to crawl around the filthy county jail floor. What's worse, without a chair, I couldn't shower. It was HUMILIATING. And the thing is, I can FEEL the lower half of my body I just can't move it, so this was all physically painful as well.[83]

When he starts serving his time in prison on drug charges, he has his wheelchair back but because of the lack of accessibility, he is put into the solitary confinement cell because it is the only one that accommodates his wheelchair. Carey helped other inmates, many of whom were unable to read and write, and then began reading legal documents about his own case and writing to every politician he could.[84] It paid off when he became an inmate rights advocate at the prisons he was in and he was able to get a bogus gun charged tossed out, so left his lifetime prison sentence after three years. He also continued writing hip-hop music while in prison. Little did he know that his graphic memoir would help inspire the global Krip Hop Nation movement.

Moore says reading *Sentences* made him want to tell a Krip Hop story in graphic novel form and helped cement his focus on uplifting Black disabled musicians worldwide.[85] In his graphic novel, Moore interweaves some of his own real-life story as a disabled Black teen watching rap music unfold in 1980s NY City with a young, modern-day, wheelchair-using Black woman, Roxanne, who becomes a teenaged superhero when she "brings disability Justice into Hip-Hop."[86] She discovers Krip Hop Nation and begins writing her own Hip-Hop songs, which gives her confidence and transforms her wheelchair into superhero Hip-Hop machine with drum machines, music samplers, and turntables, and it becomes a wheelchair that can fly and time travel. At the end of the comic, she travels to the past to meet a young Leroy Moore, who uses a walker and was not able to participate in the freestyle rap cyphers of his youth so he had to look on from outside the rap gathering. Roxanne arrives from the future to tell young Leroy that he will be the founder of Krip Hop Nation and then she blasts her Krip Hop social justice lyrics throughout NY City to let the Hip-Hop world know it should never exclude disabled Hip-Hop artists.[87]

Krip Hop Nation even inspired its own animated music video by Kounterclockwise for the song, *Whip* (2013).[88] Kounterclockwise calls itself an Alternative Punk-Hop act. They are the wife and husband team of Kaya Rogue (co-producer, co-writer, engineer, singer, and musician) and Deacon Burns (MC, producer, songwriter, musician, and engineer), who became a wheelchair user in 2007 from an accident.[89] Burns wrote the lyrics for "Whip," which tells the story of police violence against Black men through a scenario of Deacon and Kaya getting pulled over by pig-faced police and then jailed on bogus charges. When Deacon gets to make his one phone call from jail, he calls Leroy Moore of Krip Hop Nation, who summons a Krip army to save them, complete with a disability-specific "bat signal" in the sky – the universal access symbol of a figure in a wheelchair.[90] Disability music culture scholar Anthea Skinner says the lyrics and symbols in the "Whip" animated music video connects to other disabled musicians, the solidarity in the disability community, and to superheroes in comics

> As the Krip Hop Army appears over the horizon, the song's lyrics remind us why battles against institutions like the police force must be done in solidarity and not alone: 'But if you make a stand against the government they got the nerve to label you a terrorist. Ain't that a b #! Revenge for those left stranded alone in the darkness full of bullets. And all the cats that you shot in the streets, claiming that they had a gun when you knew it was a wallet.' As the Krip Hop Army appears, it is clear that their strength and formidability comes as a result of their various disabilities, not despite them. They appear as cyborgs, with their high-tech adaptive equipment indistinguishable from their physical bodies.[91]

The Leroy Moore character in the video is drawn in traditional superhero fashion, complete with red and purple tights with a large "L" on his chest. Skinner says,

> This depiction inverts the stereotypical trope of the 'super cripple' because Leroy's superpowers come not from his positive attitude, or from overcoming some presumed personal tragedy, his strength, like that of the circus performers in "Freaks," comes from the tightknit community

> of disabled people who surround him…. [This video] situating Leroy's superpowers within a strong community setting makes him and his power more relatable and realistic.[92]

The music video shows not only the oppression disabled people face, especially if they are Black, but also the power disabled people have when they join together to fight that oppression. The creators of "Whip" show that "by banding together, the vulnerability that they experienced as disabled individuals becomes a strength, allowing them to defeat their oppressors," Skinner adds.[93] She says the music video ties to themes that played out in multiple countries when disabled people came together to form the disability rights movement in both the USA and the UK and lobby for its disability rights laws (1990 ADA in the US and 1995 Disability Discrimination Act in the UK). "As the protestors fighting for the Americans with Disabilities Act [in the 1980s] proved, a dedicated group of disabled people fighting for their rights can change the world as much as any army," Skinner concludes.[94] In the same way as graphic memoirs by disabled people become sites of "productive resistance,"[95] *Whip* merges Hip-Hop lyrics, music, and animation to resist and challenge society's ableism and violence toward Black disabled people through disability solidarity. An anthem to bring the disability community together, the last scene of the music video sums up their mission succinctly: "Whip inequality. ~Kounterclockwise."[96] Kounterclockwise continues to merge music and animation with films such as the "Sugar Machine," (2022), "The Great Adventures of Kounterclockwise" (2017), and "Kounterclockwise in Forever-Land" (2014).[97]

Disabled musicians and counter-discourse

Like the memoirs that Price and Couser say become counter-discourse to challenge society's negative stereotypes about disability, disabled musicians also produce lyrics and performances that resist the discrimination and ableism they have experienced. Disabled musicians are reacting to the exclusion they felt as well. British Cultural Studies scholar George McKay detailed the history of disabled musicians in popular music in his 2013 book *Shakin' All Over*, focusing on the ways disabled performers of popular music "have addressed disability: in their songs, in their live performances, and in various media presentations." The book has a significant focus on popular music performers who became disabled from polio in post-World War II Britain and North America;[98] singers and musicians like Dinah Shore, Donovan, Judy Collins, Joni Mitchell, and Neil Young.[99] McKay says polio survivor Ian Dury became "the highest profile visibly physically disabled pop artist in Britain" from the 1970s into the 1990s.[100] McKay says Dury "produced a remarkable and sustained body of work that explored issues of disability, in both personal and social contexts, institutionalisation, and to a lesser extent the pop cultural tradition of disability."[101] McKay adds that his disability-themed songs can be read as "inventive and provocative 'narratives of corporeal/cultural difference', in Rosemarie Garland Thomson's terms."[102] Dury's counter-discourse as a disabled singer/songwriter can be seen in his many songs that explore his childhood with polio and his treatment as a disabled person in Great Britain. McKay explains that "some of Dury's songs from the height of his success draw directly on his own medical autobiography, in particular those five childhood years of institutionalisation" at a charity home for disabled children.[103] Dury had a rebel punk music aesthetic and when he heard about the United Nations creating the International Year of the Disabled Person in 1981, he found that idea patronizing and wrote the song "Spasticus Autisticus," which many nondisabled people found offensive (it was banned by the BBC), but many in the disability community said the song was an anthem of disability protest. McKay says the line in the song, "You can read my body but you'll never read my books" illustrates that Dury's lyrics were a counterpoint to his body, which "The Normals" read as visibly disabled by polio (he had a small left arm due to polio). But sometimes, McKay adds, "his body was his book, as he wrote autobiographical and observational lyrics about disability, and then performed those stories on stage."[104] Dury set a precedent for disabled artists and writers in the future who would create counter-discourse about their own bodies in their comics, graphic memoirs, graphic novels, and stories using animation.

But the disabled pop music performers McKay writes about are mostly white. Leroy Moore, a Black disabled writer, poet, and community activist, founded Krip Hop Nation in 2007 because he knew Black disabled musicians were ignored in the history of music, and the new music genre that came along in the1970s, rap/hip-hop, was created by Black and Latino men who often did not acknowledge disability and were many times openly misogynistic and homophobic. Moore said in 2021:

> The thing that I see in hip-hop [is] that mental health is talked about a lot, but we don't move further into disability, we don't move into physically disabled artists, artists that have autism, artists that are blind, so that push needs to happen.[105]

Moore began highlighting disabled hip-hop artists in the early 2000s after discovering other disabled Hip-Hop artists on the early social media site, Myspace. In 2006, Moore produced a three-part series on the topic on KPFA's "Pushing Limits," a disability news, arts, and culture radio show in Berkeley, California.[106] The first part of that series featured Preechman, the first hip-hop artist to use crutches.[107] Originally from Haiti, Preechman was raised in New York after coming to the United States as a child to get treatment for his legs, which were disabled from polio. The other episodes talked with DJ Quad from the Hip-Hop group, 5th Battalion, who is Latino and quadriplegic,[108] playwright Eisa Davis, deaf dancer/actor Fred Beam, and the first Deaf hip-hop group, Helix [now Helix Boyz].[109] Moore also had a platform by writing for *Poor Magazine*, which is published by “a poor people led/indigenous people led non-profit, grassroots, arts organization dedicated to providing revolutionary media access, arts, education and solutions from youth, adults and elders in poverty across Pachamama.”[110] Moore had a *Poor Magazine* column called Illin’ n’ Chillin’ and also wrote prolifically about Krip Hop Nation’s activities and artists. As Krip Hop Nation’s tagline says, it is “more than just music,” so the organization “goes beyond producing music and the bling-bling associated with Hip-Hop; the movement is about advocacy, education and overcoming oppression.”[111]

Moore plans an expansion of Krip Hop Nation into the Krip-Hop Institute, which will be an actual physical space with a recording studio, a performance and visual arts space, and a library/archive about disabled musicians from around the world.[112] But the principles of Krip Hop remain the same by specializing “in the accurate representation of those who are marginalized, especially disabled, Black, and the intersection between the Black disabled community therein.”[113] The Krip-Hop Institute values equity and opportunity. Since its beginning, its founding tenets reject ableism, sexism, and racism, in favor of building unity within the international disability community and acknowledging the many disabled ancestors whose lives go mostly unacknowledged. The Krip-Hop Institute articulates its values as

1. Use politically correct language.
2. Not to put down other minorities.
3. Use our talents to advocate and teach not only about ourselves but also about the system we live under as it pertains to being a person of color in conjunction with having a disability.
4. Challenge mainstream and all media on ways they frame disability.
5. Increase voices that are missing from within and in the popular culture.
6. Recognizing our disabled ancestors, knowing that we are building on what they left us and nothing is new, just borrowed.
7. To increase disability solidarity and collaboration around the world.
8. Help to increase the visibility in Black museums, cultural centers of Black disability art, and music and historical involvement in artistic/activism of the times.
9. The Disability Justice’s ten principles[114]
10. Be a space for the Black community to gain disability/Krip-Hop political education, cultural expression, and activism, while understanding the historical importance of Black disabled individuals at various different time periods in history.[115]

Krip Hop Nation reaches out to other marginalized groups in hip-hop, as well as disabled Hip-Hop artists in numerous countries. In 2009, Krip Hop

Nation joined with the LGBTQ community for a one-day event at the University of California-Berkeley called Krip Hop Homo Hop. Moore said in 2010:

> These are two groups that Hip-Hop has not included. Bringing those two groups together really erases all the negative politics between all these groups because we discover that we all have the same experiences. We talked about our movements, breaking stereotypes and breaking down the barrier between these communities.[116]

Krip Hop Nation now has hundreds of disabled musicians internationally in its network, and in 2016, Moore went to South Africa to make contact with the many disabled or Deaf musicians there. He met Simon Manda of *THISABILITY* newspaper in South Africa on Facebook in 2014, and they wanted to profile the 70 disabled or Deaf musicians they knew of in South Africa. They met with disabled Pretoria hip-hop artist Jonathan Groenewald, whose hip-hop name is 2J Harmonix.[117] In July 2019, Krip Hop Nation hosted Disabled African Musicians Summer Bay Area Festival at the Ed Roberts Campus in Berkeley, Calif., spotlighting "artists with disabilities from Zimbabwe, the Democratic Republic of Congo, Uganda, Tanzania, and South Africa. Featured artists included Francine Atosha Mbusa Lusumba Luc of the Congo and Archy Nathaniel Gomba of Tanzania."[118] Moore also tries to empower all creative artists with disabilities to address "the alienation and marginalization of creatives with disabilities from mainstream media and socio-economic platforms."[119]

Music scholars, Black studies scholars, and Disability Studies scholars have turned their attention to the Krip Hop phenomenon and its intersectional movement. In his article in the *International Social Science Review*, Matthew Gavieta employs a Black feminist disability framework in his analysis of Krip Hop, which he calls "one the most progressive underground movements in the music industry."[120] A Black feminist disability lens can examine "the intersectional nature of oppression" for Black disabled people.[121] As Chris Bell called it, "white Disability Studies"[122] grew from the Eurocentric societies of the UK and North America, but the Black feminist disability framework, Gavieta says, "has serious potential for creating intersectional approaches, defogging the stigma of disability in the Black community, and forming a unified political movement that can be a powerful voice for multiply marginalized identities."[123] This framework connects perfectly with the Krip-Hop movement, Gavieta says, because "Krip-Hop is intersectional advocacy in the form of music. It challenges society's racist and ableist views, criticizing police brutality, racial profiling, and the barriers that disabled Americans face on a daily basis."[124]

The Black feminist disability framework is an apt one because Krip Hop and disabled musicians who are Black or Latino or Asian or LGBTQ or female are helping society focus on the intersectional nature of Disability Studies. In 2021, a collaboration of Black disabled performers and their art and music won an Emmy when three disabled poets/singers/rappers created the signature song for the 2020 Netflix documentary on the Paralympics, *Rising Phoenix*.[125] Krip Hop Nation co-founder Keith Jones, rapper Georgetastic (George Doman), and singer Toni Hickman blended their talents for the song. Doman, who has CP, said in *The Guardian*,

> I used to tell my friends my disability is my superpower. What are the chances that now, during the coronavirus, we're doing this song, in a movie about the Paralympics, and the film ultimately is about disabilities being a superpower, and I'm one of the spokespeople for the song? It's just sad that it's taken so long.[126]

Jones and Hickman say they are pushing back against society's ableism, racism, and sexism that tries to define them

> For artists like Jones, who has cerebral palsy, finding a place in mainstream media has been difficult. He explained how ableism is as much a barrier as sexism, racism or genderism. They told me, 'We don't know how to market a dude with cerebral palsy in hip-hop,' so you don't!' Jones said.
>
> Rapper Toni Hickman said she was naive to ableism until she became disabled herself. 'I was the ignorant one,' said Hickman, who overcame a brain aneurysm and stroke, 'just like I had to learn to tie my shoe with one hand, you just learn to adjust.'[127]

Disabled people of color are telling their stories through Hip-Hop around the world. DeafKid (Kevin Walker), a British rapper, tells his story of being Black and Deaf in Great Britain through his lyrics and also creates an autobiographical manifesto for the hearing world with lyrics like "Listen with your eyes – no lies" and his explanation of all the beautiful aspects of sign song.[128] As a Deaf rapper, Walker says that "I was inspired to forge my own path in the music industry. I loved the creativity of making my own beats and rhymes which would speak to deaf people just as much as they would hearing people."[129] Walker and director Charles Dennis created the musical short film *Silent World* to explore what it was like to be Black and Deaf in the UK during the Covid-19 pandemic. The filmed screened at the Slamdance Film Festival in the US in 2022. Earlier it was part of BBC Arts' Culture in Quarantine initiative, which collaborated with disabled artists to create content that went into homes in Great Britain during the pandemic lockdown.[130] A review of it said: "*Silent World* deftly demonstrates what it must be like for Deaf people – especially people of color – to function in our cacophonous world, its point intensified via the prism of an all-too-real pandemic."[131] Deaf rappers have become so mainstream that two Deaf rappers, Sean Forbes and Warren "Wawa" Snipe, performed the sign language version of Hip-Hop songs from noted rappers Dr. Dre and Eminem at the half-time show during the U.S. Super Bowl in February 2022.[132] Forbes is a co-founder of D-PAN, the Deaf Professional Arts Network in 2006 that seeks "to make music accessible to the deaf and hard of hearing community by creating accessible music videos featuring deaf talent in front and behind the camera."[133] In 2015, D-PAN expanded its mission by creating D-PAN TV The Sign Language Channel, which provides music videos, stories in ASL, a Deaf issues program, interviews, news, a learn ASL for kids show, a women's program, and much more all in sign language.

In 2021, Genentech, a biotech company that developed a new treatment for spinal muscular atrophy (SMA) in 2020, decided to support the SMA community and its representation by funding a music video that was fully created by people with SMA. The senior director of marketing at Genentech Michael Dunn said the company met with people with SMA and found "reoccurring themes – that people with disabilities are underrepresented or misrepresented in media and social media."[134] So the company hired singer-songwriter James Ian, filmmaker Dom Evans, and well-known YouTuber couple Squirmy and Grubs (Shane Burcaw, who has SMA, and Hannah Aylward, who is nondisabled) to create the music video, which premiered on YouTube in early November 2021. The music video was directed remotely by wheelchair-user Evans, who was in his bed in Michigan, where he is in the least amount of pain, using his iPad to direct the shoot in Southern California. Evans said he hopes his remote directing can be a model for how disabled people can create media from anywhere. "From a practical standpoint, it wasn't that challenging. I'd love to make a TV show this way," Evans said. "There's no reason I couldn't direct a big project this way, with an on-set director that listened to what I needed and got the shots."[135] The music video, *Spaces*, features adults and children with SMA and their families in pictures shown over lyrics that say, "I'm not invisible. I'm an original." and "If there is one thing to see, it's my humanity."[136] It also shows the wedding of YouTubers Burcaw and Aylward.

Other disabled musicians are addressing the access issues in the United States music and entertainment industries. In January 2022, Lachi, a blind, Black singer/songwriter, and wheelchair user Gaelynn Lea, a singer-songwriter/violinist, officially launched Recording Artists and Music Professionals with Disabilities (RAMPD) to promote disability inclusion in the music industry. RAMPD says it "is working to shift how artists with disabilities are perceived in the music industry — moving away from inspirational tokenism, and towards competent and competitive professionals who deserve respect and recognition in their chosen field."[137] Lachi says on the organization's website that after she and other disabled artists met online with the New York chapter of the Recording Academy in May 2021, it became clear that "there is a serious lack of visibility, access, and representation for professional disabled artists."[138] Lachi says she wants to be a role model for other disabled people who want to work in the music industry. Lea said she wants to make music venues more accessible to performers and audience members. As a wheelchair user, Lea adds

> The places I can play are extremely limited. This is a huge issue that a place like the Recording Academy really can be taking the lead [on], because the reality is, with so many venues, I can't get in the door, I can't use the bathroom, I can't get to the room where the stage is, and that's just if I want to attend a show. If I want to perform at a show, a lot of the time, I can't access the stage because there's no ramp. The green room is not even on my radar right now because it's so difficult to find the basic accessibility requirements … So the reality is, the barrier to entry is so high right now. It's a really urgent problem.[139]

DJ's, music producers, and those who use modular synthesizers also need access to a wide variety of music-making technology. German DJ Bertolt Meyer, who was born without his left lower arm, uses a modular synthesizer that he can plug into his bionic prosthesis using a SynLimb.[140] He says this technology has been a game changer for him making music: "I used to feel quite limited when playing the modular in comparison to my two-handed colleagues. Now I feel that I can do some things even quicker than they can."[141] Meyer would like all disabled musicians to have access to the technology they need to be part of the music industry. Internationally, many disabled musicians are getting more attention, like singer Prudence Mabhena in Zimbabwe, who has arthrogryposis and was the focus of an Academy Award-winning short documentary in 2010, *Music by Prudence*.[142] In addition to continuing her singing career, she also works as a vocal trainer, choir coach, and speaker.[143] The indie rock-pop band Rudely Interrupted in Australia, whose five of six members have disabilities such as autism and Down syndrome, has been on the international music scene for more than a decade; the band played at the United Nations in 2009.[144] Rudely Interrupted discussed the impact of the global pandemic that began in 2020 at an event at the Brunswick Music Festival in Melbourne, Australia in March 2022. They said that home-based creativity and music during the Covid-19 lockdowns "presented a unique opportunity to use this [online video chat] technology to improve access and inclusion in the music industry for people with disability worldwide."[145] Just like the disabled memoirists and disabled graphic novelists, musicians, creative artists, and performers are transforming culture with their own brand of counter-discourse to illustrate to the world that they are empowered, independent media makers with something to say. And they are an intersectional group who speaks not just for disabled people generally but for disabled women, for disabled people of color, for disabled people who are LGBTQ, and for people who do not speak verbally or speak in a sign language. As Krip Hop Nation co-founder Keith Jones said, people with disabilities are still struggling for civil rights in most places.[146] "It is the last great struggle," he said, but hopes he can be a role model for other disabled people, especially youth with disabilities. These young people need to know that the world of music, art, writing, and production are going to be open to them. "We need to understand that all kids – whether they're on a ventilator, in a wheelchair, or have dyslexia – all have the ability to learn," Jones said.[147] Disabled musicians also intersect with a variety of performed music that has long entertained audiences. RAMPD co-founder Gaelynn Lea composed original music for "Macbeth on Broadway" in 2022,[148] signaling that disabled musicians are connected to all forms of music, past, present, and future.

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6 “Giving everything they have”

Documentaries illuminate disability experiences

Documentaries have a significant place in the representation of the disability community even before many disabled people found a camera and started to document their lives themselves. Disabled artist Riva Lehrer’s concept of “mirror hunger” is germane to documentaries about disability.[1] As an artist who paints portraits of important disabled people, she says members of the disability community are hungry to see themselves represented accurately (or at all) in media and the arts. Lehrer says the focus of her paintings of disabled people is to

> Profile a community that is vibrant, attractive and that you’d want to join. Discovering community is transformational. One of the greatest problems we have is that people don’t want to identify as disabled. Disability community fosters our identity, encourages our cultural development and reflects the complexities of our experiences.[2]

Her definition of “mirror hunger” is “the longing for a reflection one can claim as one’s own.”[3] All the documentaries in this chapter connect disabled people to images of their community and its members who inspire pride and a sense of belonging to the disability community. Even the hard truths of the disability experience in the documentaries strengthen the community because finally the larger society may learn that it is mired in ableism and an unequal status for disabled people. As *Crip Camp* co-director Jim LeBrecht, who uses a wheelchair due to spina bifida, says, “Who is more likely to make a film about police violence against the disabled and Deaf? Who better to make a film about the life-and-death consequences of rolling back the ACA (U.S. Affordable Care Act) and Medicare?”[4]

Disability film curator Lawrence Carter-Long cites the significance of director Frederick Wiseman’s controversial *Titicut Follies* (1967) that documented the inhumane treatment of inmates diagnosed with mental illness at the Bridgewater (Massachusetts) State Hospital for the Criminally Insane, where it was filmed. Carter-Long says, “Wiseman’s ground-breaking documentary illustrates the power of non-fiction filmmaking and unwittingly illustrates how society can change, be forced to change, when harsh truths are

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exposed. When filmmakers attempt to reveal what was previously 'safely' hidden away behind closed doors."[5] The government of Massachusetts banned the release of *Titicut Follies* to the general public for 24 years, but in the late 1980s, the families of several inmates who died sued the state hospital and gave Wiseman and his attorney a way to get the ban lifted.

The documentary showed inmates being kept naked and filthy, force fed, and taunted by guards. Attorney Steven Schwartz, who represented one of the families whose loved one was restrained for 2½ months and given such high doses of psychiatric medicines that he choked to death on his food, said if the documentary had been released in 1967, it could have helped reform barbaric psychiatric hospitals. "There is a direct connection between the decision not to show that film publicly and my client dying 20 years later, and a whole host of people dying in between," says Schwartz, who became an advocate for mentally ill people after seeing the film in law school.[6] The late film critic Roger Ebert's review in 1968 said *Titicut Follies* showed the reality of the inhumane treatment of those with mental illness at the hands of all the staff at the state hospital. He said,

> One 'paranoid' patient, told he has shown no improvement, argues that the prison is making him worse, not better. This sounds like the simple truth, and the film leaves us with the impression that institutions like Bridgewater are causing mental illness, not curing it.[7]

Although people with mental health disabilities were the subjects, not the directors, of *Titicut Follies*, the film illustrated the power of documentaries to more accurately show the lived experiences of disabled people and to document ableism and abuse as well.

Even before disabled people were documentary filmmakers, documentaries became more collaborative so that the perspectives of disabled people were front and center. Several developments in the 1980s converged to make documentaries about disabled people important tools to empower people with disabilities *and* educate the general public. The first was technological. The introduction of the camcorder by Sony in 1983 transformed the ability of the average person to shoot their own videos. The heavy bulky video cameras used by the television broadcasting industry did not transport well and needed two people to operate because of the separate audio recorder.[8] Swiss filmmakers who study camera innovations said in 2020:

> Video and DV camcorders were quickly adopted in the late 80s and 90s by independent documentarists. They led to a more home-movie-like visual quality of films but also produced very intimate films.[9]

This change in cameras allowed disability organizations worldwide to begin shooting their own documentary-style content to promote their work with disabled persons. Barbara Kolucki, an international expert in inclusive communication, said beginning in the late 1970s the content of these films about disability shifted to more empowering and became less framed within the medical model or a pity or "Supercrip" approach.[10] With actual disabled people involved in these documentaries, they steered away from the gaze of many nondisabled filmmakers, which Markotić says often focuses on how the disabled body does and does not "work" and spends much of a documentary's time on a person without a disability transitioning into a life in a physically disabled body.[11]

Kolucki says another event informed better disability community documentaries – the 1981 International Year of Disabled Persons (IYDP).[12] Through that event, many across the world were trying to actively change societal attitudes toward disability for the better. The United Nations (UN) General Assembly voted in 1976 for the year-long 1981 designation:

> The theme of IYDP was 'full participation and equality', defined as the right of persons with disabilities to take part fully in the life and development of their societies, enjoy living conditions equal to those of other citizens, and have an equal share in improved conditions resulting from socio-economic development. Other objectives of the Year included: increasing public awareness; understanding and acceptance of persons with disabilities; and encouraging persons with disabilities to form organizations through which they can express their views and promote action to improve their situation. A major lesson of the Year was that the image of persons with disabilities depends to an important extent on social attitudes; these were a major barrier to the realization of the goal of full participation and equality in society by persons with disabilities.[13]

With this focus on visibility, Kolucki said the world soon noticed disabled people's growing contributions to mass media as hosts of TV programs, as actors, and as the subjects of documentaries. The UN even held a seminar and published a booklet about positive portrayals of people with disabilities in the media.[14]

Because disability content in video media grew in the years after 1981, the international disability organization Rehabilitation International assembled a catalogue in 1998 of disability films from around the world, the *International Disability Video Catalogue*. Kolucki, who co-edited the catalogue, said that the catalogue was an attempt to counter the negative and inauthentic depictions of disability that still existed – ones that "instil fear, pity or shame in millions of people around the world."[15] The philosophy behind the Rehabilitation International video catalogue, she said, was to educate, advocate, and entertain audiences so everyone can work on creating a better future for disabled people worldwide. "Much of this can be changed by increased production and viewing of positive, entertaining media portrayals where people with disabilities are speaking for themselves," Kolucki said.[16]

Many of the non-fiction videos in the catalogue focused on disabled role models in two meanings of the term: that disabled people's real experiences could educate other disabled people about possibilities for their own lives and that the videos could be role models for empowering media portrayals for future media about people with disabilities. Most of these documentaries were not made by a disabled filmmaker, but the collaborative production style meant disability groups and other disabled people endorsed these documentaries. Outside the disability community, community collaborative filmmaking grew out of ethnographic filmmaking. Ethnographic filmmaker Sarah Elder, who collaborated with indigenous people in Alaska, says community collaborative filmmaking is:

> A space for filmmakers to learn to pose the questions they do not originally know to ask, a place where film subjects select the fragments of their reality they deem significant to document, and a moral place where subjects and image makers can mediate their own representation.[17]

An early example of a director wanting to empower and honor the community he or she is highlighting in a documentary is French filmmaker Nicolas Philibert's "In the Land of the Deaf" (1992). He said his goal with that film was "to show another vision of deaf people, who most of the time are considered poor, handicapped people, which means [seeking audience] pity, etc."[18] He wanted his film to change this negative image people have of the Deaf community. Philibert hoped his film would illustrate their dignity and rich cultural language. He admitted that before he directed the film, he thought sign language was a lesser language, but instead he learned that sign is a rich and nuanced language like any other. "I started to understand that it is the most cinematic language because you represent [sign language] in space," he said.[19] He became interested in deaf culture and deaf language through that film.

Rehabilitation International's catalogue placed Philibert's film in its Role Models category because it is filled with deaf adults and deaf young people in France telling the world about their lives. One deaf teen in the film said that she had never seen any deaf adults until she and her family travelled to US-based Gallaudet University for deaf students. When she saw all the happy deaf people at Gallaudet, she said, for "the first time I could see a bright future for me."[20]

Filmmaker and communication studies professor Sam Avery embraced disability community collaborative filmmaking when he partnered with psychiatric survivors in Western New York for the 2013 short film, *Not Without Us*. The collaborative film began with psychiatric survivors who explicitly said they did not want to be photographed, filmed, or interviewed. But as trust was established, the psychiatric survivors at Mental Health Peer Connection (MHPC) began to speak on camera about what it is like to be mentally ill and rejected by society. A woman who led MHPC saw the benefit of the film, saying "If we want to be heard, we need to talk. If we want people to know our stories and know what we've been through, we have to talk."[21] Avery reported that a man, who was skeptical from the first day Avery arrived with his video camera, came to see the film as a way to tell society about the trauma he experienced from being "zombalized with these medications."[22] The film let people diagnosed with mental illness "finally be heard," Avery said.[23] He said in the end, the journey to make the community collaborative film led to an "equitable balance of power."[24] Avery added, "Six months earlier this group had dismissed media as destructive and discriminative, and now they themselves had participated in media making, which provided them a sense of empowerment."[25]

Groups of disabled people in many countries began documenting their unique activities on film. Russell Vickery, a member of the New Zealand Paraplegic Boat Team and author of a 2021 book on the team, says the boat team came together as a way to highlight the 1981 IYDP, and it led to the team crossing waterways in New Zealand, England, Canada, Peru, Egypt, and Samoa for the next 20 years. The boat used by the team moved by the cranking of bicycle pedals by hand to turn the propeller.[26] Two locations for the boat team, Egypt and Peru, became documentaries. From the Egypt trip, Vickery says that the film *Chariots on the Nile* was created and aired on New Zealand television in 1995. *Paras in Peru* covered the team's 1991 trip there and was shown in 1992 on New Zealand television.[27]

Mitchell and Snyder say documentary films about disability create a kind of global map, guiding audiences and disabled people themselves to a more inclusive future. They discuss disability documentaries in a number of countries that "capture events in the past and the present in order to project future disability landscapes that might prove fully inhabitable, accepting and potentially realisable."[28] Similarly, many disability-collaborative documentaries provide disabled role models for a variety of careers and ways of being in the world. For example, the 1994 U.S. documentary, "Look Who's Laughing," profiled disabled comedians. It starred Kathy Buckley, who has hearing loss, J.D. England, who is paraplegic, Chris Fonseca, who has cerebral palsy (CP), Alex Valdez, who is blind, Geri Jewell, who has CP, and Brett Leake, who has muscular dystrophy.[29] When "Look Who's Laughing" first appeared on PBS, TV critics were enthusiastic in their response:

> Lynn Elber of *The Associated Press* wrote that it 'defies us to keep our prejudices about the talented men and women we're laughing with, not at.' John J. O'Connor of *The New York Times* said, 'As bridge builders, these performers are extraordinarily skillful.' And Drew Jubara of the *Atlanta Constitution* called the show 'by turns outrageous, provoking and moving.'[30]

The producer of *Look Who's Laughing*, R.J. Johnson, cemented a connection between disability content and U.S. public broadcasting (PBS) that one could argue exists to this day. "If it wasn't for PBS and the Corporation for Public Broadcasting, there would be no '*Look Who's Laughing*,'" Johnson said in 1994.

> We're living in a climate where a lot of people are taking shots at the viability of PBS and claiming cable is, like, the alternative. But that's just not true. I was rejected by all the normal commercial television outlets. The reaction I got from everybody who could finance a show or air a show like this was, 'I don't get it.' They didn't understand that standup comics who had a disability could be incredibly funny.[31]

Johnson, a nondisabled actor who wrote freelance articles about the entertainment industry to make extra money, met several disabled actors when he did an article for the *Los Angeles Times* on the topic. His *Times* article on disabled actors working in prime-time series resulted in him co-producing a documentary about that subject, *Breaking Ground*. It aired on independent TV station KTLA in 1987 and that is where Johnson met stand-up comics with disabilities.[32]

Public broadcasting once again lent its support to disability documentary content in 2021. The PBS station in New York City, WNET, backed multiple disability documentaries. Day Al-Mohamed, a blind woman who is the director of an award-winning Civil War documentary, *The Invalid Corps*, directed the first film for the PBS American Masters disability history streaming series.[33] Al-Mohamed's first short documentary for the series in July 2021 was about the life and accomplishments of deaf Hollywood stuntwoman and speed racer Kitty O'Neil.[34] In October 2021, PBS *American Masters* aired the documentary, *Becoming Helen Keller*, as the finale episode for its 35th season. Moving away from *The Miracle Worker* version of Keller's life, TV Insider's Matt Roush said the documentary focused on "her adult legacy as an advocate for social justice and people with disabilities."[35] Multiple Tony- and Emmy award-winning actor Cherry Jones reads Keller's writings in the documentary, with actor/dancer Alexandra Wailes adding American Sign Language (ASL) interpretation of Keller's words – and writer/rapper Warren "WAWA" Snipe providing ASL interpretation throughout the documentary.[36]

Another important documentary that brought disability rights to more attention, *When Billy Broke His Head and Other Tales of Wonder* (1995), showed the power of a first-person perspective in disability documentaries. The film's creator, Billy Golfus, acquired a traumatic brain injury (TBI) from a motorcycle accident and used the film to explore his new identity as disabled man and the discrimination against him and other Americans with disabilities. Its tagline is "a video first-person road movie about disability, civil rights, and the search for intelligent life after brain damage."[37] It was filmed in the first years after the 1990 Americans with Disabilities Act granted full civil rights to disabled people and quickly reveals that more than laws have to change if the disability community is to enjoy full equal rights. The film skewers disability bureaucracy and the media's role in misrepresenting people with disabilities. "Like almost everyone, I thought disabled people were supposed to act tragic and brave, or cute and inspirational, but these people weren't sticking to the script," Golfus says in the film[38] as he goes to disability rights protests and interviews many significant American disability activists such as Ed Roberts, a polio survivor who lived in an iron lung and is considered the father of independent living in the US.[39] The film is a pointed social critique of ableist America that still resonates several decades later. *When Billy Broke His Head and Other Tales of Wonder* won the Sundance Festival's Freedom of Expression Award in 1995 signaling that a major film festival was beginning to take disability documentaries seriously.

At about the same time, Disability Studies scholars David Mitchell, who is a wheelchair user, and Sharon Snyder were creating what they call their "communal documentary" from interviews and performances they filmed at a national conference on Disability & the Arts at the University of Michigan in 1995, *Vital Signs: Crip Culture Talks Back*.[40] Originally, they thought the film would be about Disability Studies and disability politics but as they filmed, they began to see a documentary about disability culture take shape. They also saw the documentary as a way for their subjects to push back against negative stereotypes and the societal stigma of disability.

> We sought to make our own subjects larger-than-life. While people with disabilities usually find themselves equated with contagion, undesirability, wasting innocence, or tragedy, our video evokes an intimacy with its interviewees and performers. In this sense, *Vital Signs* embodies a visual revolutionary praxis: get the faces of our community on screen, step back, and watch people fall in love with them rather than assume a false repugnance or artificial distance.[41]

They clearly structured interviews to show wheelchair users not as powerless but as powerful, by using a low angle that would visually elevate their disabled subjects above viewers. Their goal was to counter the objectification of disabled people that is so often in films. *Vital Signs* allowed disabled artists, activists, writers, and scholars to "out themselves" as vibrant members of disability culture.

> Historically, disabilities have been narrated as private and individual concerns to be banished to the closets or attics of houses and institutions. We sought to argue that the danger of this social construction of disability has isolated people with disabilities from public view and inhibited them from political organization,

Mitchell and Snyder said.[42] Little did they know that they were creating *Vital Signs* at a time when more documentary films were beginning to address disability in a more empowering way:

> Unknown to ourselves, *Vital Signs* would be part of a bona fide movement of film and video in the mid-1990's that would seek to narrate the experience of disability from within the disability community itself. Experimental documentaries such as *When Billy Broke His Head* (1995), *Twitch and Shout* (1995), and *Breathing Lessons* (1996)—all award-winning productions—surfaced alongside our own less extravagantly funded documentary. What these visual productions all shared was a commitment to telling stories that avoided turning disability into a metaphor for social collapse, individual overcoming, or innocent suffering. They shared a refusal to capitulate to the trite and sentimental productions of mainstream Hollywood films and mass-produced television.[43]

Mitchell and Snyder sought to create a document via film that would record and stimulate the disability culture movement. Carol Gill, professor of psychology at the University of Illinois-Chicago, says in *Vital Signs*, "I believe very firmly in a disability culture, and if we didn't have one, we should!" Mitchell and Snyder say they

> Were driven by our sense of the 'newness' of this formulation for many people. People with disabilities occupy a unique relationship to the theorization of culture because our physical and social experience differs so radically from those of other minority communities.[44]

Enough funding for disability documentaries, as for other filmmakers, was a hurdle for Mitchell and Snyder. Because of nudity in some of the performance art in *Vital Signs*, they knew it would not be suitable for public broadcasting, and because of its humanities focus, it would not be funded by disability organizations that only gave money to disability projects with a rehabilitation or practical application. They said that *Vital Signs* cost about $9,000 to produce, most of which came from a surgeon at the Mayo Clinic, who was an alumnus of Northern Michigan University where Mitchell and Snyder were faculty at that time. As a comparison, they say Billy Golfus received $200,000 in funding to create *When Billy Broke His Head*.[45]

In a similar fashion to *Vital Signs*, *Code of the Freaks* (2020) grew from within disability culture. Chicago-based playwright, novelist, and long-time disability rights and culture activist Susan Nussbaum had a desire to interrogate the power of Hollywood's misrepresentation of disabled people and the impact that had on actual people with disabilities. Nussbaum produced the film and collaborated with director Salome Chasnoff, as well as Disability Studies faculty at the University of Illinois-Chicago, Carrie Sandahl, and

Alyson Patsavas.[46] The final 68-minute film project began more than ten years before and an 18-minute version could be accessed on Vimeo since 2011. *The Chicago Reader* aptly reported in 2021 that the documentary highlights the ableist images of disabled people that have been in Hollywood films since their beginning.

> *Code of the Freaks* shines a searing light on ableism in mainstream film. During the age of the #OscarsSoWhite and #MeToo movements, when Hollywood's discriminatory practices are coming under increased scrutiny, *Code of the Freaks* gives much-needed voice to the myriad ways disabled people's lives are directly impacted by these stories.[47]

But even some disabled people have been upset by the film's critique of some beloved films, Sandahl said. "We don't present a progress narrative." Patsavas says,

> We are telling a horror story of the impact of these images on disabled people's lives . . . and, much like some horror films, we leave the audience feeling terrible, and that's the intent, that frustration of a happy ending.[48]

In 2017, Australian filmmaker Sarah Barton, the mother of a daughter with CP, introduced audiences to disability rights activists in the UK, USA, and Australia through her film *Defiant Lives*.[49] Since 2003, Barton had been producing a disability-focused documentary series for Australian television, *No Limits*. With *No Limits*, she said, "We wanted to put disability on television. I think the Australian community has a lot of goodwill for people with disabilities, but there's a lot of ignorance about what the issues are."[50] After she received a Churchill Fellowship in 2010, Barton began travelling to the US and the UK to interview disability rights activists there and gather archival footage. Her focus for *Defiant Lives* was to show how the disability rights movement globally has transformed the world for everyone. The film has interviews with more than 30 disability rights activists of the past four decades and more than 600 clips of archival footage and photographs from around the world.[51] A disability arts organization in the UK said that with its thorough historical research and comprehensive interviews, *Defiant Lives* sends a message of Disability Pride:

> That pride shone from each interviewee, from every person captured on the grainy footage of protests and from the audience in the cinema as they witnessed the battle that led to many of the disabled audience members being able to access the film at all.[52]

Collaborative disability documentaries are transforming culture by giving voice to disabled actors, a disabled artist, a university instructor and parent who speaks with a letter board, and a Deaf transgender man raising funds for his top surgery.

Several media programs at residential camps for adults with disabilities led to multiple documentaries and even to feature films. At Camp Jabberwocky on Martha's Vineyard in Massachusetts, adults with intellectual disabilities took a video class from camp director Arthur Bradford and together they created, *How's Your News?* (1999), a documentary in which a group of those adults conduct unique "man-on-the-street" interviews while on a cross-country road trip.[53] *South Park* creators Matt Stone and Trey Parker became executive producers of the feature-length documentary, which was shown on HBO, PBS, and Channel 4 in the UK. The *South Park* duo later helped develop the documentary into a TV show on MTV in 2009.[54] *How's Your News?* produced a political documentary special in 2012 after they visited both political conventions.[55]

More recently, Zeno Mountain Farm in Vermont brings disabled and non-disabled people together to make collaborative films, and two of its founders, Peter and Ila Halby, had worked at Camp Jabberwocky and saw the need for adults with disabilities to build community with each other and with non-disabled people. Zeno's stated mission "is to support lifelong friendships and opportunities for people with and without disabilities and other marginalized communities." They come together for creative projects such as making films or creating art and sports activities such as skiing or adaptive windsurfing.[56] In 2015, Zeno's filmmaking project to shoot a Western became the subject of the documentary, *Becoming Bulletproof*. It put the voices of disabled people, especially those who want to work in film, television, and theatre, front and center, so they could share their desire for a creative community. *The New York Times* said this about the documentary:

> Besides the usual ordeals of moviemaking — missed lines, bad cues, lighting woes — Mr. Barnett looked at the cast and crew's friendships and struggles. These men and women with Down syndrome, cerebral palsy and other disorders speak frankly (and with plenty of humour) about sexuality, relationships and anxieties. There's some sadness and tears, but never pity or mawkishness.[57]

AJ Murray, a Black man with CP, sought out the Zeno film project, so he can begin his journey to become an actor but also to find a community of like-minded peers. He said:

> At camp I feel significance, dignity, and purpose. Other people are relying on me and I am contributing. At home I don't feel like I get to contribute. I don't feel like I get to contribute in society. I don't get a say; I feel so worthless.[58]

Zeno's feature film efforts continued with its first feature-length scripted film, *Best Summer Ever* (2020). It is a musical that is the first Screen Actors

Guild-registered film to have a majority of its cast and crew be people with disabilities, one of whom is AJ Murray.[59]

King Gimp (1999) showed the educational and artistic journey of disabled artist Dan Keplinger; it won the 2000 Academy Award in the short documentary category and a Peabody Award. Filmmakers Susan Hannah Hadary and William A. Whiteford of the University of Maryland Video Press began filming Keplinger when he was still a child at a school for disabled children and followed him until he graduated from Towson University in Maryland. Funded by a federal grant to document the inclusion of disabled children in public schools, the filmmakers followed Keplinger for 13 years, watching Keplinger grow into an artist and university student.[60] And he became more than a documentary subject when he attended Towson University as mass communication major. While at university, Keplinger wrote 80 pages of script for the documentary. It was a kind of video memoir of his life as a wheelchair user who has CP and paints large canvases using a paintbrush attached to headgear.[61] By that point, the film had run out of funding, but the premium cable network in the US, HBO, came on board to help edit the 100 hours of footage and distribute the film on its network. But HBO wanted to complete the documentary in ways that Keplinger felt would silence him. Even though his CP affects his speech significantly, he fought to speak verbally in the film. His halting speech gives the documentary a depth of authenticity and keeps the audience's focus on him. Although he says his speech frustrates him, he doesn't want others, or even a computer device, to speak for him. "My thoughts race to my mind, slowed to a near standstill when I begin to talk," Keplinger said.[62]

The documentary, *My Dad Matthew* (2017), ties to similar themes of an authentic disabled voice when someone has a speech disability. This short documentary explores the relationship of a disabled father and his nondisabled son. *My Dad Matthew* introduces audiences to Matthew Wangeman and his son, Elijah, 14 in the film. Wangeman is a Northern Arizona University (NAU) Disability Studies instructor with CP who uses a head stick and letter board to communicate but that has little impact on the loving relationship he and his son have. To Elijah, disability is not "other" or different; it's just his Dad. As a seven-year-old, he believed a wheelchair was a rite of passage and that he would get one as an adult.[63] The film is part of Wangeman's ongoing mission to change people's negative attitudes toward disability. The director of *My Dad Matthew*, John Schaffer, was a filmmaker studying special education at NAU when they met. Wangeman saw a documentary as an extension of his teaching that disability is part of the natural diversity of the world. "I don't think disability is a bad thing, it is just different. And what makes it bad is the attitudes that other people have about disability," Wangeman said.[64] What Elijah teaches the world (and Matthew) through the film "is disability to him is typical," he says.[65]

Several collaborative documentaries of note introduced audiences to people with disabilities who use AAC devices to communicate. *Wretches & Jabberers* (2011) follows two previously institutionalized autistic men who communicate via typing, Tracy Thresher and Larry Bissonnette, as they travel the world meeting with other autistic self-advocates in Sri Lanka, Japan, and Finland in an effort to "change prevailing attitudes about disability and intelligence."[66] Canadian Estée Klar, founder/director of the Autism Acceptance Project and mother to an autistic son, wrote about the power of the film to potentially change misinformed views about autism: "Larry, Tracy, Henna, Chammi, Naoki, and Antti are few among many who ask us to move our view of 'disability to a positive place' (to quote Tracy) so that all lives may be included and valued."[67] Similarly, 2017s *Deej* amplified the voice of a nonspeaking autistic person. Fellow nonspeaking autistic man, Jeremy-Sicile-Kira, wrote about how he felt seen when *Deej* was released:

> Truly *Deej* is a movie about a person who is a thinking human being who greatly truly is just wanting a life like anyone else. I justly hope that people watch this movie and greatly understand what our lives are like when we have understanding educators and communities.[68]

Austin Unbound (2011) focuses on a segment of the Deaf community that is rarely seen – transgender Deaf people. The co-director of the documentary Eliza Greenwood said at a screening that her background as a Gallaudet University graduate and as a hearing sister fluent in sign language drew her to the project. The production team wanted the film to be situated in the "queer-centric and sign-centric community," she said.[69] The film is unique in that it is entirely in ASL and captions/subtitles; even the voices of hearing people are not heard. Austin makes it clear throughout the documentary that he identifies as a straight man. He gained support from the Deaf community in his journey. He and his friends created a fundraiser for his top surgery with an ASL Comedy Night. Austin performed, as did a number of other deaf supporters. "The Deaf community would be different if not for him. Austin is such a leader in the trans world. He's so open. He doesn't care what others think," a friend from the Comedy Night says in the film.[70]

Sins Invalid: An Unshamed Claim to Beauty (2013) explores how sexuality and queer identities also connect with disability. The self-produced documentary about the Sins Invalid performance project especially focuses on disabled artists of color and queer and gender-variant artists. Sins Invalid the organization says the short documentary highlights Sins Invalid performances because they

> Serve as an entryway into the absurdly taboo topic of sexuality and disability. Since 2006, our performances have explored themes of sexuality, embodiment, and the disabled body, impacting thousands through

> live performance. The path to the stage and the performance itself manifest a new paradigm — disability justice.[71]

In a like fashion, Jane Hash, a woman with Osteogenesis Imperfecta, created a 71-minute video called *Plain Jane The Shockumentary* (2013). A review in *New Mobility* magazine said that

> It shows it all, her sexuality (and bisexuality), her friendship with her transgender friend, her studying of Eastern medicine, even her attending a nudist pagan festival and her romantic interlude with her girlfriend and a male friend whilst there (in a tent no less).[72]

These disability community collaborative documentaries push back against the will of nondisabled documentary directors who don't want to collaborate with their disabled or Deaf subjects. Markotić says that too often nondisabled directors focus on one or more newly disabled people, emphasizing what the directors see as a now unmanageable disabled body that is controlled through admirable courage.[73] Markotić says that the nondisabled documentary directors play into what viewers desire to see: "non-disabled audiences of these documentaries want to know primarily about that moment when a non-disabled person becomes disabled and how that changed them."[74]

The notion that documentaries about disabled adults can inspire children with disabilities in their future lives can be found in the childhood of Antiguan-American model Aaron Rose Philip, who is now the first Black, transgender, and disabled model to be represented by a major modeling agency.[75] When Philip, who has CP and uses a wheelchair, was still in primary school in New York City, she met Sidiki Conde, a dancer, drummer, and polio survivor from Guinea, who speaks and performs at schools. Conde dances on his hands because polio affected his legs and made him a wheelchair user. A few months later, Philip went to a drumming and dance lesson with Conde, which appeared in the 2013 documentary by Alan Govenar, "You Don't Need Feet to Dance."[76] In addition to the thrill of appearing in the documentary with her hero, it is clear in Philip's memoir that meeting an accomplished disabled artist like Conde set her on a path of possibilities. Conde has founded music and dance troupes of disabled people in both Guinea and the USA. Philip wrote about the significance of seeing an active wheelchair-user artist as a fifth grader:

> I hardly ever saw anybody in a wheelchair really in the swing of things. I hardly ever saw people with disabilities in a movie or on TV (as opposed to able-bodied actors playing disabled people). I hardly ever saw anyone like me working in banks, in schools, as managers of supermarkets or other kinds of stores. I worried that when I grew up, I'd be an invisible [woman]. Sidiki Conde's visibility with his disability gave me

> a whole lot of hope. That's why meeting him at such a young age was HUGE for me.[77]

Disabled artists continue to be the subject of documentaries and in 2021, a mainstream actress with a disability, Selma Blair, agreed to a documentary about her multiple sclerosis (MS) diagnosis and subsequent life. As a newer member of the disability community, she asked that the documentary team take advice from disabled filmmaker and FilmDis founder Dominick Evans. The director of the documentary, Rachel Fleit, who has the autoimmune disease alopecia universalis, which causes hair loss, says that being a bald woman helped her relate Blair's journey.

> Fleit said that Blair exercised no editorial control over the film, adding that the endeavour would succeed only if the actress 'was willing to show the world what really happened — that brutal intimacy and honesty that you just don't see — and she was totally open to that.'[78]

Blair said that she wanted the documentary to be transparent about her ups and downs with MS because she wanted to be open about the trouble she has with her body and brain. She hopes others with newly diagnosed disabilities that affect their brains and/or bodies can find benefit in her honesty. And there may be tangible benefits of other people with MS seeing the documentary. Cynthia Zagieboylo, the president and chief executive of the U.S. National MS Society, said:

> When someone like Blair is open about her illness, 'people can feel less alone in facing the challenges of their own M.S. People experiencing potential symptoms might recognize something. It could lead to an earlier confirmed diagnosis of M.S., which means people could get treated faster and that leads to better outcomes. By her sharing her journey with the world in a really authentic way, there's really no downside to that.'[79]

Documentaries that were made in collaboration with their disabled subjects have transformative power on global culture, but that power becomes supercharged when disabled people direct their own documentaries.

Disabled documentary filmmakers

As noted, disabled people have been participating in the creation of documentary films for many decades. But they are erased sometimes when they direct; Steven Delano directed *No Bigger Than a Minute* (2006) but does not receive director credit on the database of TV and film, imdb.com. [80] Delano, who has dwarfism, had long worked as a producer and director in film, TV, and theatre, when he turned the camera toward his personal story to explore living with dwarfism and the media's impact on society's perceptions of little people.[81] Delano used the film as a way to build his self-acceptance of his disability and interviewed young performers with dwarfism, future Emmy-winning actor of *Game of Thrones*, Peter Dinklage, TV actress Meredith Eaton, and rapper Bushwick Bill. He wanted his film to move away from the cliched tropes that have long depicted people with dwarfism in popular culture.

> It was important to me that *No Bigger Than a Minute* be different from other films about dwarfism. I was determined to avoid sentimentality and adjectives like 'inspirational.' Because of my interests in pop culture, I wanted to make something more on the stylistic side. And something with some attitude.[82]

His documentary appeared on the long-running U.S. public broadcasting series, *POV*, which has been showcasing independent non-fiction films since 1988.

Unlike Delano's access to film and television production tools, other disabled people who wanted to shoot documentary films probably benefitted from more broadly accessible film technology. Nihan Işıkman says that the launch of the Apple iPad in April 2010 and soon after the video capabilities of the iPhone gave all filmmakers a more manageable way of shooting a film digitally. "It is possible to find aesthetics that derive from the portability of the mobile device, such as the immediacy, intimacy and the everyday, which a smartphone camera can deliver and which become a unique aspect of mobile filmmaking."[83] These aspects of digital video fit well with the intimate stories, many times about their own lives, that disabled documentary filmmakers were trying to tell.

Socially, disabled people were beginning push back against misrepresentation of their lives in all forms of mass media. Jen Brea, director of 2017s *Unrest*, says that

> What happens in the fiction world is a reflection of the broader culture's erasure of disability and illness, and I think that it does bleed into the documentary. You see it in the lack of any specific funds to support directors with disabilities, and the lack of spaces for conversations focused on these issues, not to mention that disabled filmmakers are rarely invited to participate in existing spaces and conversations about diversity, which usually focus on gender and race.[84]

She adds that "In fiction, people with disabilities or illness have always been magical, inspirational, sexless, tragic or triumphant—the catalyst for the real protagonist's transformation."[85] Brea, who has myalgic encephalopathy/ chronic fatigue syndrome and shot much of her film from bed and via video chats, used her documentary film to tell the story of her and others' journey through a little-understood chronic illness.

Director Jason DaSilva had been making films for more than a decade when he began feeling the effects of his MS diagnosis, which he began documenting in his 2013 film, *When I Walk*. His documentary was shown at the Sundance Film Festival and later won an Emmy after it aired on the PBS show, *POV*. DaSilva says it was uncomfortable to turn the camera on himself, but he did so for seven years to film *When I Walk*. "I wanted to try to do something that has rarely been done before: to show the scientific and medical model of disability alongside the social and personal model of disability," DaSilva said in 2013.

> This really meant thinking outside of the box, and I found refuge and inspiration from viewing my creative self before I got multiple sclerosis. I would suggest having a good, strong, creative base that supports you throughout your filmmaking efforts, which could go on for longer than expected.[86]

DaSilva followed up *When I Walk* with 2019s *When We Walk*, which is about his effort as a disabled New Yorker to connect with his son, who has been taken to Texas to live with his ex-wife.

DaSilva also shot a short documentary for *The New York Times* about accessibility issues in New York City and how poor disability services and institutionalization in Texas meant he could not move to that state to be with his son. Another non-film project that was an off-shoot of *When I Walk* is AXS Map, "a crowd-sourced tool for sharing reviews on the wheelchair accessibility of businesses and places." Many New Yorkers are unaware that sometimes nine out of ten businesses on one block of New York City could be inaccessible, DaSilva says.[87]

As a native of Venezuela, Victor Pineda, who uses a power wheelchair due to a genetic muscular condition, uses his work as a producer and director to highlight experiences for disabled people, including him, from around the world. In 2021, he was working on the documentary *Unconfined*, in which he travels internationally to many inaccessible locations to reinforce that his life as a disabled man can't be "confined."[88] Pineda says that his disability experience inserts a unique perspective into documentaries: It is

> Like a key that unlocks insights into compelling themes such as vulnerability, imagination, creativity, resilience, persistence, courage and the absolute absurdity of life in and of itself. I am drawn to these topics as my stories explore frailty, loss, redemption and strength.[89]

Pineda began making documentaries while still an undergraduate at the University of California-Berkeley. In 2001, he wanted to create a documentary series called "Disabled Nations, Disabled Peoples" to show the lives of disabled people internationally. In 2001, Pineda shot the first short documentary, *In Cuba, Disabled*. "I wanted to get out and see life from a different perspective and document it," he explained in 2003. "What is life like for a disabled Cuban? Does the system care for its people in a different way than the U.S. does? We don't have universal health care like Cuba does, but they have much more limited funds."[90] He created a foundation in 2006, now called World Enabled, that is the founding sponsor of the It's Our Story video project in the United States. This project is a mixed-media digital history archive of the disability experience in the USA. More than 1,300 people from the disability community in 200 locations have been interviewed since it began in 2005.[91]

Many of these documentary projects have shown the way for other disabled people to focus on their own documentary idea. Jim LeBrecht, co-director of the Oscar-nominated 2020 documentary *Crip Camp*, says that disabled documentary filmmakers come to projects with innate problem-solving skills: "People with disabilities have had to figure out how to live in a world that wasn't built with them in mind; many people with disabilities excel at troubleshooting and figuring out work-arounds."[92] For example, from her bed, Brea shot footage of other people with chronic illnesses using video conferencing and/or sending a crew to shoot footage while she directed remotely.

LeBrecht said that the goal for disabled filmmakers is "to tell our stories because we can do so from our own perspective, not one that is filtered through someone else's lens."[93] Another obstacle disabled filmmakers face is an ableist society that medicalizes everything about disability and refuses to see disability as part of the diversity of American society. Documentary filmmaker Day Al-Mohamed, who directed *The Invalid Corps* (2019) about a mostly unknown regiment of disabled soldiers in the U.S. Civil War,[94] said in 2018.

> The biggest roadblock to building a career, especially now, I think, is the invisibility of disability. There is a lot of discussion about diversity in the industry; about women in film and women directors; about #OscarsSoWhite and the need for more LGBT representation,

but there is no discussion of disability.[95] Al-Mohamed is a blind woman of color who is a member of the LGBTQ community. Society recognizes that there is bias and discrimination against women, people of color, and the LGBTQ community, she says, but society's denial of the longstanding prejudice against the disability goes unacknowledged. That means filmmakers with disabilities "are not seen as legitimate professionals within the industry," she adds. Jen Brea remembers being invited to an event at a major international film festival that didn't have wheelchair access.[96]

Many filmmakers say that having a disability enhances their ability to do the collaborative work that making a film requires. LeBrecht says,

> I want to express how valuable our experience with our disabilities has been to help us lead and retain the people around us. When you must rely on others to help you through the day, be it with dressing, eating and personal care, you learn how to clearly instruct your crew.

Al-Mohamed agrees, adding:

> Filmmaking, by its very nature, is creative, and having unique and different perspectives enriches the content, the craft and the team. It is about working together to reinforce each other's strengths and cover for each other's weaknesses; it is about planning and last-minute problem-solving, with the goal of creating an amazing piece of work. Disability, at its heart, is about adapting to the environment, collaborating with others and accommodating each other to be successful.[97]

LeBrecht reminds everyone that disabled people "make films that go well beyond the worn-out tropes of what being disabled and Deaf is all about. Being able to view a broader perspective on life benefits us all."[98] Disability Studies scholar Simi Linton, who is a wheelchair user, and Christian von Tippelskirch together directed 2014s *Invitation to Dance*, which combined Linton's personal story with late 20th-century societal changes for the disability community.[99] Alexander Freeman, who has CP and directs from his power wheelchair, has been a producer and director of both fictional and documentary films. His documentaries touch on a variety of disability issues, such as *The Last Taboo* in 2013 about disabled people's experiences with sex and relationships,[100] and his more recent film in progress in 2021, *Indomitable, A Love Story*, about his life with his partner Orina and their child, Maya.[101]

Director Reid Davenport, who also has CP, creates documentaries with a political edge. He has three short-film series about the barriers people with disabilities face in everyday life, *Ramped Up* (2016), *A Cerebral Game* (2015), and *Wheelchair Diaries: One Step Up* (2013). Davenport says,

> Each film implicitly and explicitly explores issues and concepts such as accessibility, the medical model versus social model, marginalization, societal response to disability, and the Americans with Disabilities Act. These films together create a more three-dimensional portrayal of disability than what is commonly shown in the media.[102]

Two other disabled directors explicitly take on media misrepresentation of disability. Adrian Esposito, who is autistic, directed 2016's *Diffability Hollywood* to explore a variety of aspects of disability in Hollywood, from film and TV representation to the experiences of disabled actors working in the industry.[103] Director Jenni Gold, who has muscular dystrophy and uses a power wheelchair, delved into Hollywood's longstanding fascination with disability in 2012s *Cinemability: The Art of Inclusion*. *Variety* said of the documentary: "Jenni Gold surveys more than 60 members of the Hollywood community about how people with disabilities have been portrayed in (and excluded from) film and TV in this essential, conversation-sparking documentary."[104] As a wheelchair user since the age of seven, Gold jokes that "since her director's chair goes 12 miles an hour, she is the first to arrive on set."[105]

Cheryl Green, who identifies as someone with multiple invisible disabilities, co-directed 2016's *Who Am I To Stop It*, which looks at the lives of several people with TBI and the role of art in their lives. Their directors' vision stated:

> We made this film to be a non-medical look at life with traumatic brain injury (TBI). It explores the role art plays in many people's lives for connecting communities, bringing peace and peace of mind, engaging in work, and exploring life. It was important for us to make a film from within the community, and Co-Director Cheryl Green identifies as a peer with TBI. The film deliberately has no imagery of car wrecks, hospital stays, or rehabilitation. There are no interviews with doctors, providers, or family members. Rather, we focus on peers with TBI for the storytelling, and we witness them interacting with their families and communities, through challenges and triumphs. The film contains very difficult topics like talk of suicide, homophobia, housing instability, and isolation. It was important for us to not avoid these very real parts of the disabled experience.[106]

Rodney Evans, who has retinitis pigmentosa, investigated the creative journeys of other artists with visual impairments in his feature-length documentary, *Vision Portraits* (2019). A reviewer with a visual impairment herself says that the film shows some of the diversity of human experiences with blindness:

> There's a sense of poetry, light, and movement in *Vision Portraits,* a full sensual experience. The film's visual perspective shifts often, demonstrating for the viewer how each artist sees. No one person is blind in the exact same way. Many people with low vision have small areas of light and colour in different corners of the eye. Some see white. Others see colours constantly, creating artwork only they can see. When the film turns to Evans's perspective, we are thrust into a very different story, as he travels to Europe on his quest to restore his vision. He discusses the ways in which being a Black gay man adds an extra strain to his life as a blind person.[107]

Conclusions

As all these disabled directors illustrate, documentary film is becoming a significant way for disabled people to tell their stories, and for the global disability community to satisfy its "mirror hunger." And disabled directors can now be guided by an organization for them, FWD-Doc, Documentary Filmmakers With Disabilities, which was created in 2018 by disabled filmmakers and a producer ally. Its mission is "to increase the visibility of, support for, and direct access to opportunities, networks, and employment for D/deaf and disabled filmmakers. We aim to foster greater inclusion of D/deafness and disability within the broader entertainment industry."[108]

The founding of FWD-Doc, Documentary Filmmakers With Disabilities is already transforming the media culture in the USA and the UK. In the UK, the British Film Institute Doc Society Fund collaborated with FWD-Doc: Filmmakers with Disabilities in 2021 "to create an industry resource aimed at ensuring disabled-accessible and disabled-inclusive documentary filmmaking and exhibition."[109] Called the FWD-Doc Engagement Pack, it

> Provides practical resources and information for the film industry on how to engage effectively, respectfully and creatively with disabled film talent and audiences. It is designed to empower all areas of the independent film sector; from distribution, exhibition and festivals to decision makers across awards and funding, and filmmakers.[110]

Filmmakers who look at the Engagement Pack will learn about ableism, the social model versus the medical model, and how to collaborate with disabled people as filmmakers and consultants.[111] The goal is for documentary filmmakers to learn about the actual lived experiences of disabled people and how to make the films they create fully accessible to the disability community. If a country's filmmakers truly engage with the disability community, it will be transformative for the entire society.

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7 Becoming visible people with nonvisible disabilities crafting media content

The world of disability representation in media is typically presented as a disabled/nondisabled binary but that excludes millions of people with nonvisible disabilities and chronic illnesses or pain that ebb and flow in the lives of their bodies. These missing media representations have actual consequences in the lives of audience members who share these conditions hidden from view. In the early days of the AIDS epidemic, U.S. AIDS activist Peter Staley says that he went to a doctor because he saw the American NBC television network film *An Early Frost* in November 1985.[1] The Emmy-winning film was the first TV film to focus on a character with AIDS (played by Aidan Quinn), a closeted gay lawyer who returns home to his family after his HIV diagnosis and finds rejection and fear from his parents and sister after he comes out and reveals his diagnosis. "*An Early Frost* attempts to dispel myths about AIDS communicability in a poignant scene in which Quinn's Michael tries to show his mother affection" with a kiss, IMDB said.[2] *The Washington Post* TV reviewer called it "the most important TV movie of the year."[3] Another important moment that brought a better understanding of AIDS to television came from *Designing Women* (1986–1993) creator Linda Bloodworth-Thomason, whose mother died of AIDS transmitted through a blood transfusion in 1986.[4] Bloodworth-Thomason says that her mother, a straight white woman, was treated as horribly as the gay men with AIDS in the hospital unit, so she created a *Designing Women* episode in October 1987 to focus on the discrimination people with AIDS faced in the 1980s. She called the episode "All the Right People Are Dying" to reflect a statement she heard while in the hospital with her mother.[5] The episode depicts a young gay interior designer (played by Tony Goldwyn) asking the interior designer characters to design his funeral. The episode featured accurate information about HIV/AIDS and interrogated the stigma people who are HIV-positive face. U.S. English professor Nels Highberg says that episode that he saw as a gay teen comforted him with its information about how to stay safe, as well as confronting societal prejudice. "This episode was created to counteract the revolting realities people with AIDS experienced daily," Highberg says in 2022 essay on *Designing Women* and HIV/AIDS. For him, sitcoms

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"were bright spots amidst the otherwise ruthless fear."[6] The early media content about HIV/AIDS also taught viewers about U.S. disability rights laws. A scene in the 1993 Oscar-winning film starring Tom Hanks, *Philadelphia*, acknowledges the U.S. disability rights law, the Rehabilitation Act of 1973, as a remedy for the employment discrimination that the *Philadelphia* character with AIDS faces because AIDS is discussed as a disability under that law in the film.[7] The Americans with Disabilities Act (ADA), passed in 1990, explicitly states that people with HIV/AIDS or any condition, whether visible or not, are protected from employment discrimination under the ADA. However, *Philadelphia* illustrates why people with nonvisible conditions and chronic illnesses should be involved in media productions that talk about their experiences. The production team of *Philadelphia* had to pay the family of Geoffrey Bowers, the gay man with AIDS who inspired the film, $500,000 for misappropriating his story.[8] Being HIV-positive has become a chronic illness where medications are available to treat it; however, in countries without access to the medications, AIDS continues to be deadly. On the African continent, AIDS is still one of the top five causes of death.[9]

Because of stigma, ableism, and homophobia, many people who are HIV-positive in the U.S. entertainment industry keep quiet about their status for years. Actor and Broadway musical star Billy Porter did not reveal his HIV-positive status publicly until he starred as an HIV-positive character on U.S. FX network's *Pose* (2018–2021), which is a drama about the Black and Latino LGBTQ+ community's ballroom scene in New York City in the 1980s and 1990s. Porter discussed his HIV-positive status in 2021, although he contracted HIV 14 years before. He said he is done with the shame that caused him to hide his diagnosis

> This is what HIV-positive looks like now. I'm going to die from something else before I die from that. My T-cell levels are twice yours because of this medication. I go to the doctor now – as a Black, 51-year-old man, I go to the doctor every three months. That doesn't happen in my community. We don't trust doctors. But I go to the doctor, and I know what's going on in my body. I'm the healthiest I've been in my entire life. So it's time to let all that go and tell a different story. There's no more stigma – let's be done with that. It's time. I've been living it and being in the shame of it for long enough. And I'm sure this will follow me. I'm sure this is going to be the first thing everybody says, "HIV-positive blah, blah, blah." OK. Whatever. It's not the only thing I am. I'm so much more than that diagnosis. And if you don't want to work with me because of my status, you're not worthy of me.[10]

Porter embodies the tension about "coming out" with a nonvisible disability/chronic illness. (He has been out as a gay man since he was 16). U.S. gender and Disability Studies scholar Ellen Samuels says people with nonvisible disabilities/

chronic illnesses must contend with the expectations of nondisabled people, whether revealing their disability or pretending they don't have one. She says

> Such constant and invasive surveillance of nonvisibly disabled bodies is the result of a convergence of complicated cultural discourses regarding independence, fraud, malingering, and entitlement; the form it takes almost always involves a perceived discontinuity between appearance, behaviour, and identity.... Thus many nonvisibly disabled people may feel that our choice is between passing and performing the dominant culture's stereotypes of disability.[11]

Samuels suggests that even the field of Disability Studies gives much more attention to disabilities that are apparent. Disability Studies' "focus on the visual continues to render nonvisible disabilities *invisible* while reinforcing the exact cultural reliance on visibility that oppresses all of us."[12] Disability activists with nonvisible disabilities have long challenged even the disability community to understand that true disability justice includes people who may appear to be "nondisabled." U.S. disability activist and writer Cal Montgomery, writing in 2001, says that nondisabled people have defined disability by tools such as wheelchairs, white canes, or hearing aids, and the disability community has defined disability by visible barriers to accessibility such as stairs or lack of ramps or braille. Montgomery says, the disability community must also reject the binary of visible/invisible disabilities to become a true cross-disability community. Montgomery explains to the disability community:

> Dismissing that which is unfamiliar to us as 'invisible' (and suggesting that it cannot be discerned rather than that we have not learned to discern it) is another way of throwing the responsibility for social justice back on the individual who carries the burden of injustice.[13]

The thing that binds the disability community, whether their disabilities or chronic illnesses are apparent, Montgomery says, is the fight against societal ableism and oppression.

With the advent of newer forms of mass media and social media, people with nonvisible disabilities/chronic illnesses have many methods to reach people worldwide through their YouTube channels, Instagram feeds, participation on reality TV, and even creation of documentaries or entertainment programming on traditional television networks. Theirs is also a story of defiance of the general public, and even medical professionals who don't believe their bodies and/or minds are disabled.

Social media

Disabled YouTuber/artist/activist Annie Segarra (they/them), who identifies as a queer, Latina person with multiple nonvisible disabilities, is one of a group of younger people with nonvisible disabilities/chronic illnesses who have used media to tell the world about how they move through life. Segarra said in 2019

> I've been creating content on the Internet since I was a teenager and it just came very naturally to me to write about myself in public. I think that's a very millennial thing. I'm 28 and as my life progressed in terms of like coming out as queer and then as my health started to decline ... I discovered that I had a degenerative condition called Ehlers-Danlos syndrome (EDS). I was always documenting things for myself in kind of a cathartic way and then [I] ended up also being able to provide solidarity for other people and kind of an education or awareness for people that didn't know that these experiences existed.[14]

Segarra says that online communities taught her about EDS in the first place and helped her build an online friend group of others with EDS and other chronic illnesses. Finding support online "affirmed her existence as a young person who needs mobility aids," Segarra says.[15] Segarra explains that the chronically ill communities on Facebook, Twitter, and Instagram provide significant resources to make connections and find information. Segarra wants to use their online platforms to show others with nonvisible disabilities that they can also tell their own stories about their experiences. The Invisible Project, a magazine for people who live with chronic pain started by Nicole Hemmenway,[16] who lives with chronic pain, highlights the work of Segarra who says that "by being so visible herself ... offers a window into a world that so many people rarely even consider is there."[17] Segarra's efforts are also addressing the erasure that they say happens for people whose disabilities and chronic illnesses are not as readily visible. "There's a whole culture and understanding of disability and chronic illness. We've been so erased in the mainstream and that means many have no idea how to communicate or work with us," Segarra says. As a child, Segarra thought being an actress was what was in the future but says their true calling is as an online storyteller of the nonvisible disability experience: "Rather than act out someone else's words, I want to tell my own stories and those of other marginalized people and how they live their lives. I'm excited to do that."[18]

Segarra has been using multiple social media platforms for a number of years, combining videos, images, text, and hashtags (#TheFutureIsAccessible, #AmbulatoryWheelchairUsersExist) to educate others. In 2018, Segarra used two images in a Facebook post to describe their journey as an ambulatory wheelchair user, for which Segarra has faced discrimination and even harassment. Segarra describes the two images of their head lying in bed:

> Two photos of Annie from the shoulder up laying [cq] in bed on a red pillow and with red comforters. Text on her forehead reads, 'I'm in bed because I need to be' second photo continued, 'Not because I want to be' and in the background of the first photo red text with black borders

> are on her pillow, 'EDS, myalgia, arthralgia, injury, chronic pain, POTS, dysautonomia, tachycardia, chronic fatigue, low blood pressure.[19]

In the text of the Facebook post, Segarra explains the many adjustments and accommodations made each day:

> I am chronically ill. I spend a lot of time in bed. When I say that, some people respond with 'Oh, you're so lucky you get to be in bed all the time.' and I am lucky and grateful to be a chronically ill person that HAS a bed and a roof but I know that's not what they're implying. The response suggests that the time I spend in bed is restful, that it is for leisure, but that just isn't true.
>
> I'm an ambulatory wheelchair user, I use my wheelchair for anything where I'm expected to stand longer than my limit of about a minute, so around the house and whenever I can, I am pushing my limits and attempting to walk and stand. Pushing my limits, beyond pain, beyond fatigue, costs me.
>
> It's a cycle of trying my hardest and get knocked down and into bed and repeat.
>
> My hardest may not be a lot to the untrained eye, a flight of stairs is a MOUNTAIN for me (dysautonomia, tachycardia, shortness of breath, possible fainting), 5 minutes of standing is a 2 hour squat for me (fragile joints leave most of the work to the muscles).
>
> Today my puppy had two accidents that I had to bend down and clean up; bending down is being hung upside down for 15–30 minutes. Two pee clean ups landed me in bed for the rest of the day.
>
> In a society where our value is determined by how much we produce and contribute, I lye [*sic*] in bed riddled with guilt, with a burning desire to get stuff done, not just chores or errands but the things I truly love doing and I can't.
>
> My muscles are made of thick burning lava, the world is spinning, my breathing is painfully slow and deep, and my eyeballs keep trying to get a look at my brain and instead sink into the darkness.
>
> But from the outside, it just looks like I'm lounging in bed, especially if I end up on my phone in attempts to distract myself.
>
> The instinct to look at a person in bed as being 'lazy' and judging them for it is not an easy thing to unlearn but I hope that the more we talk about it, the more understanding there will be.[20]

In 2019, Segarra follows up this Facebook post on her Annie Elainey YouTube channel with a video called, "Ambulatory wheelchair users exist." Segarra states the facts at the beginning:

> Wheelchairs are not just for people with no mobility in their legs. Wheelchairs are mobility aids for a variety of different disabilities.

> People may need to use a wheelchair, whether manual or electric, due to chronic pain, fainting spells, lack of stability, dizziness, chronic fatigue, muscle, joint, or skin fragility. Some people have occasional periods of paralysis; they might have lung or heart conditions, and the list goes on. Wheelchairs can also be used preventatively, to prevent flare-ups or worsening symptoms.[21]

Segarra's YouTube channel began by exploring their mental health journey and body image activism related to their eating disorder. One aspect of nonvisible disabilities that Segarra has always explored is all the nondisabled people who believe people who do not have apparent disabilities are "faking." Segarra explains in a 2016 Annie Elainey YouTube video that has 82,000+ views:

> So maybe you've seen someone parking in a disabled parking spot and then walking right into a space or maybe you've seen a wheelchair user move their legs or get up from their chair, maybe you've seen a cane or a walker user take a few steps without it, maybe you've seen younger, prettier, even larger people using power scooters at the market or at theme parks? NONE of those things imply that someone is "faking" a disability. Disabilities are diverse and fall on spectrums, many disabilities are invisible, and these false accusations of 'faking' put disabled lives at risk of harassment and violence.[22]

Segarra wants the world to know that "you cannot tell if a person is disabled just by looking at them."[23] Segarra sees the harm from media narratives about supposedly "fake" disabilities. When interviewed in 2021 by comedian Jenny Lorenzo, who also has nonvisible disabilities, Segarra tells the story of an ambulatory wheelchair user who transferred onto rides at Disney World and was later kicked in the leg by a child when she got back into her wheelchair, with approval from the father who said it was okay to harm someone he felt was faking a disability.[24] Segarra added that many TV shows and films rely on tropes of characters faking their disabilities or on the actually disabled character being the villain in the story, with disability symbolizing their evilness. Segarra says these media tropes make many people misunderstand how diverse disabilities are and that most are not apparent. But Segarra says that can change when disabled people tell the stories: "That's what is so important about having people in the writers' room and in positions of power who come from diverse backgrounds."[25]

Lorenzo, who has ADHD,[26] an anxiety disorder, and Crohn's disease,[27] interviewed Segarra as part of her Hyphenated podcast with fellow comedy star Joanna Hausmann. The English-language podcast is about the hyphenated intersection of American and Latin culture. The comedians explore what it means to bicultural. Lorenzo agrees that nondisabled people have little knowledge about diverse disabilities and that people with all kinds of disabilities have been shut out of Hollywood. Lorenzo posits that the long-term segregation of disabled people in society creates widespread ignorance about the disability community. She says nondisabled people should begin to listen to the disability community:

> How about putting us in writers' rooms, how about supporting our projects, how about diversifying your social media feeds so that you actually have disabled creators as a part of your scrolling period of your day so you get to see us as human beings.[28]

Lorenzo applauds the work of Segarra surrounding nonvisible disabilities. "Mainstream media is failing us when it comes to representation and getting authentic stories told by disabled folks," Lorenzo says, adding that "there's no excuse [for lack of inclusion] because of people like you (Annie), who exists right now and create content that is educational and informative."[29]

Eventually, Segarra is interested in using newer technologies, such as Discord – an online voice, video, and text communication service – to create content that highlights individuals of various backgrounds and identities. Segarra "hopes to help facilitate a worldwide network of patients, as well as sharing stories about disabled and chronically ill communities," according to The Invisible Project.[30] Segarra reminds everyone that it's society's ableism and the fear that accompanies it which keeps people with nonvisible disabilities hiding their conditions. They worry about employment discrimination and being called "lazy" or a "faker." "You're putting all your energy to presenting yourself in a way that is palatable to people who may exhibit ableist traits, who may have ableist opinions about you," Segarra says. This ableism becomes a barrier to many with people with nonvisible disabilities featuring their experiences in any form of social media or mass media.

However, many media creators with nonvisible disabilities and chronic illnesses face down this ableism and tell the world about their lives with nonvisible disabilities and chronic illnesses. U.S. Disability Studies scholar Susan G. Cumings studies how writers and activists with nonvisible disabilities are using a variety of media platforms to open their lives and experiences in online spaces.[31] Cumings studied three examples of online media from people with nonvisible disabilities/chronic illnesses: the Suffering the Silence photography campaign for people with conditions such as Lyme disease, HIV, and lupus,[32] blogger Danielle Myers' autobiographical photo essay, "Why I'm showing these Private Photos of My life with chronic Illness,"[33] about her daily life with rheumatoid arthritis and fibromyalgia as a mother of four, one of whom has tuberous sclerosis complex, autism, and epilepsy, and Stephen "Ste" Walker, whose photos on Facebook depicting himself with and without his stoma visible[34] and his hashtag #SickButInvisible led to other people with nonvisible conditions posting their own pictures. Cumings is particularly interested in these examples using multimodal communication (text, audio, and visual) about nonvisible disabilities on new media platforms, especially the use of photography to depict conditions that are supposedly “invisible.” She examines “the rhetorical use of photography as a medium and ‘invisible disability’ as a subject, and addressing the apparent paradox in choosing a visual medium to ‘depict’ something that cannot be seen.”[35]

Cumings’ research illustrates how people with nonvisible disabilities/chronic illnesses are a vibrant part of the larger community of people with visible disabilities. The Social Model of Disability informs her analysis:

> The social model of disability helps make clear what people with disabilities have in common: the fight against attitudinal, bureaucratic, material, and ideological barriers rooted not in the body but in the built environment, institutional practices, and the habits of thinking that shape them. The three projects studied in this essay focus on public misperceptions of ambiguous or ‘invisibly’ anomalous bodies. These are bodies said to ‘look fine’ but not experienced that way due to pain, fatigue, and other limitations both physical and the misguided expectations of others concerning what disability ‘looks like.’[36]

She says the three online projects she analyzes “promote a redefinition of wholeness.”[37] Citing Disability Studies scholar Petra Kuppers, the “participants recapture their bodies and re-mobilize their meanings.”[38] Cumings says that these projects by people with nonvisible disabilities are creating

> The metaphorical sense of visibility (as enfranchisement) in with their literal visibility in (virtual) public space. By positing that any seeable whole must be reunderstood as inevitably holding ability and disability in tension, they displace misleading and potentially disempowering misunderstandings of the relationship between signifier and signified rooted in ableist constructions of the transparency and stability of wellness and illness.[39]

She says people whose disabilities or chronic illnesses are not apparent being online helps to break society of the ableist well/unwell and abled/disabled dichotomies. Cumings explains that in the Suffering the Silence campaign, Myers, and Walker “direct their audiences not to seek or settle for seemingly easy labels, but to attend to the complex phenomenology of living with disability.”[40]

A significant aspect of Cumings’ analysis is the confirmation of the importance of people with nonvisible disabilities controlling their media representations and images, as well as leading others with nonvisible disabilities into an understanding of their own disabilities. She says:

> Furthermore, #SufferingTheSilence and the #SickButInvisible hashtag born of Walker’s rant provide space, structure, and encouragement to unknown others in a (counter)public (Asen 2000;[41] Warner 2002)[42] with whom they claim communal ties, creating virtual communities and organizational coalitions with real benefits. Each campaign succeeds, I

> argue, because disabled persons act as producers—not just appear as products—of media, controlling their own images, expanding the social imaginary by careful public pedagogy based on disability experience. In doing so, they also encourage the formation of disability identity as a valid social identity not defined by what Garland Thomson terms 'normate' conventions[43] of appearance or behaviour.[44]

Cumings says that after Walker's Facebook photos about his stoma got so much attention from others who are also #SickButInvisible, he and a friend created a dedicated #SickButInvisible Facebook page, Twitter, and Instagram accounts. They joined people together to "to form supportive and activist coalitions with diverse organizations addressing Crohn's and colitis, depression, severe anxiety and other mental health concerns, autism, discrimination against the deaf, and so on."[45] They use these social media spaces to urge others to make complaints against and protest ableism against people with nonvisible disabilities. #SickButInvisible also encourages praise of societal organizations that acknowledge and respect people with nonvisible disabilities such as the British supermarket chain ASDA that put "not all disabilities are visible" signs on its accessible restrooms.[46] Cumings says social media activities from people with nonvisible disabilities fit with what Australian disability and media scholars Katie Ellis and Gerard Goggin call citizen media from people with disability and their allies.[47] Ellis and Goggin explain that it is crucial that people with disability be viewed "as citizens who make, shape and are governed and influenced by media."[48] In contrast with the criticism of social media that it results in vapid elitism that uplifts individuals only,[49] Cumings says the social media from the people with nonvisible disabilities fosters community and disability camaraderie. She explains about the projects she studied

> They stress solidarity, community building, and the value of interdependence over individuality or earning potential. over and against the mainstream edited and polished self(ie) they stress that there are many interrelated yet highly diverse images that only together can begin to represent a person. they emphasize that modes of experience vary, and deliberately reveal complex selves through word and image, including making the supposedly private or discomforting public.[50]

Cumings' analysis illustrates how disabled creators in social media spaces are challenging ableism and fostering community for people with nonvisible disabilities and chronic illnesses.

> This is community-building and public pedagogy…. This is activism. The case studies presented in this essay demonstrate how, as long as economic and technical accessibility are pursued and assured, media tools at the disposal of disabled persons in charge of their own representation

> facilitate creative multimodal storytelling that challenges all of us to be better receivers, interpreters, and carriers of each other's stories, stories that are at once multiple and singular, fragmentary and whole.[51]

She adds that in the Suffering the Silence campaign, Myers, and Walker are also confronting people who "pity" them without diminishing the actual challenges of their daily lives with disabilities. Cumings says they "challenge audiences to take responsibility for a collective cultural failure to recognize the complexities of disability living,"[52] as disability activist Cal Montgomery[53] calls them. "Together, these projects address the objectification of disability and the disabling effects of objectification," she says.[54] People with nonvisible disabilities are creating authentic social media stories and images about their own lives, which fosters empowerment for them and for others whose disabilities are not apparent to the ableist world.

Born for Business

Many actors and reality stars have nonvisible disabilities/chronic illnesses, but most rarely discuss them in their media content. But in the modern era, some are open about them on their social media platforms and with the news media. Examples are as diverse as British actor Daniel Radcliffe (dyspraxia),[55] American singer Nick Jonas (type 1 diabetes), U.S. rapper Lil' Wayne (epilepsy), British actor Orlando Bloom (dyslexia), and American singer/actor Selena Gomez (lupus, depression, psychosis, bipolar).[56] Gomez was diagnosed with lupus in her 20s and received a kidney transplant to help alleviate lupus symptoms in 2017. She discussed her bipolar diagnosis on U.S. singer Miley Cyrus' Instagram show, *Bright Minded*, in 2020, saying having a diagnosis helped her. "When I got to know more information, it actually helps me. It doesn't scare me once I know it," she explained to Cyrus.[57] Gomez has been a strong mental health advocate, winning several awards for sharing her mental healthcare journey and supporting others.[58] She laid out her six-year mental health journey[59] in a documentary released in November 2022 on Apple TV+ called *My Mind & Me*.[60]

But a reality show in 2020, *Born for Business*, gave a voice to unknown businesspeople with disabilities, two of whom have nonvisible disabilities. The reality show on the U.S. NBC broadcast network's Peacock TV streaming platform is also a unique window into the Covid-19 pandemic's impact on people with disabilities because the pandemic began in the United States in the middle of filming of the show in Chicago, Boston, and Long Island, New York. The disabled entrepreneurs are: Qiana Allen of Chicago, who has lupus and runs a fashion business for plus-sized women with a retail store and online shopping site; Collette Divitto of Boston, who has Down syndrome and owns a bakery and a cookie brand in locations throughout that city; Chris Triebes of Chicago and Indiana, who has spinal muscular atrophy (type III) and owns music venues and plans concerts while raising his teen daughter as a single father; and Lexi Zanghi of Long Island, NY, who has an anxiety disorder while running her online shopping fashion brand and has hopes of opening a retail store.[61] Their stories are powerful as the pandemic closes everything because it is clear that their businesses are important legacies for them beyond the income they need for themselves and their families and employees. Allen discusses the vulnerability she feels as the Covid-19 pandemic hits: "My immune system is compromised because of the lupus. I feel like going outside in a bubble. I have never seen anything like this."[62]

Allen said she never wanted to reveal her personal life or background to the public but wanted to highlight the beauty and talents of plus-sized women and people with disabilities so she joined the reality show. She says the world needs to change the negative ways they view plus-sized women and people with disabilities and *Born for Business* could do that. "In order for people to start loving themselves more, they have to see more people that look like them," Allen said.[63] Allen also began a candy store and cereal bar, Munchiez, in August 2020, which serves 33 kinds of cereal, candy, milk shakes, and savory dishes like nacho fries and walking tacos.[64]

In episode 8 of *Born for Business*, Allen has a flare-up of her lupus and discusses coping with a chronic illness as an active businesswoman and mother, especially in the midst of a global pandemic. Her doctor notices she has the beginning stages of a lupus flare-up. Allen admits she had been ignoring the symptoms because she is so busy. "I kind of knew something was going on but I didn't mention it because I thought it would pass. It's just crazy because I have so much to do. And then dealing with this, I hate it," she says as she begins to cry.

> It's like I am almost trying to tell myself that I don't have it because I want to be normal. Or what people would say is normal. I don't want to be sick. I just feel like I can beat it even though I know that I can't outrun it; I just feel like I can, even though technically I can't.[65]

Allen embodies the inner dialogue that many people with nonvisible disabilities have as they negotiate their lives with conditions that increase and decrease symptoms on a regular basis but that the outside world, even friends and family, can't see.

Allen explains that as an entrepreneur, she juggles many tasks as both a boss and as someone expanding her business ventures and adding new ones. "Having to deal with a flare-up is kind of challenging because of the kind of work that I do," she says. "I am always working. I don't get the rest that I'm supposed to get."[66] She also doesn't get the relaxation she needs. She happily takes a twerk and dance exercise class because her doctor asked her to get more physically active to help control her lupus symptoms. "With dealing with lupus, I know definitely stress in general can trigger a flare-up so it is good for me to have fun like this. I don't want my work to be in vain. I want to enjoy life," she says.[67] But she gets a call from the manager of Munchiez, her new candy store/cereal bar business in the middle of the dance class. "I can't even enjoy exercise without them calling me," Allen explains.[68]

She is also trying to bring her two sons, aged 20 and 15, into her new candy store/cereal bar business, so she is teaching them business tasks as well. In one scene, she shows her sons how to register a business with the state of Illinois. "Y'all need to learn so you can do it yourself," she explains to them. Her goal is for the older son, Keenan, to run the backend of the Munchiez business. "I want him to do the inventory; to do some purchasing; just take some of the responsibility off myself and Duane (her boyfriend). "I can see him doing it but he definitely has a lot of growing to do," Allen says.[69]

However, conflict arises at Munchiez when her cousin who works for her gets into an argument with the manager and was told not to come to work the next day. Qiana tells him he has to listen to the manager. "I feel anxious having to deal with the [lupus] flare-up and thinking that I might have to slow down. There is just so much drama at Munchiez; I just can't stop working right now. It's not an option." During a meeting with the employees of Munchiez, which includes her sons, Allen reminds everyone that they need to listen to the manager and not call her with everything that happens there. Her son Keenan, who is a part owner of Munchiez, asks for his hours to be cut. When Allen asks him whether he wants to be at the meeting, he says "No" and she tells him to leave. She goes after Keenan and they have a confrontation outside; she reminds Keenan that he is a part owner of the business and he can't run away when things get chaotic. Allen begins to cry, saying "Y'all, all I got. Everything I do is for y'all." Her younger son, Kameron, hugs her. "My mama did everything for me, too, so I want to make sure y'all got what y'all need. If something happens to me, what y'all going to do," Allen says.[70] It is clearly the perspective from someone with a chronic illness who knows she might die younger than other people.

Allen gathers herself and coaches Keenan as a businesswoman/mother to advise him to let the employees know what he needs from them. They return to the employee meeting and Keenan admits that he was upset by employees arguing and explains that he wants to make sure employees have what they need. Allen reinforces that the manager is still in charge and decides to promote Keenan to assistant manager. Allen tells the camera later that "we didn't need an assistant manager. I made that decision because I wanted to show him leadership and that he's included in the business," adding that building a team of employees takes some time and that's what she is trying to show Keenan.[71] Keenan and Kameron obviously respect their mother a lot and know she is an excellent businesswoman. Keenan said about Allen in episode 5, "Whatever she puts her mind to, it's going to happen."[72]

The other cast member with a nonvisible disability is Lexi Zanghi. She is the youngest cast member, aged 22 when the series shot, and openly talks about her anxiety throughout the show and actually has an anxiety attack during the first episode of the show but the other three cast members help her calm down. Zanghi says that she had anxiety since she was a young teen but was denial about it for several years.

> I think that in high school I definitely had it, but anxiety is one of those things, I know that for a fact now, when you're going through it all you know is something's seriously wrong. You don't know why or what is happening to you. I could never describe it in words…it was just I'm sad or stressed or I just have a weird feeling, but I never knew it was anxiety. Looking back, I totally had it.[73]

She intended to go to college to study fashion merchandizing but the anxiety she felt on her first day of college after someone criticized her New York accent sent her home. With the support of her parents, she decided to use her college money to start a clothing business, Always Reason. She associates her brand with anxiety relief. She wants to create a safe space to discuss the topic with her customers.

> I'm trying to normalize [anxiety] by talking about it more. And whenever I do, half the time they usually know someone that's seriously going through what I went through, and they want me to talk to that person, or they need advice. Normalizing it and talking about it is so important now more than ever.[74]

She confronts her anxiety by making it something she can challenge with words so she feels in charge of her mental health. Zanghi says, "I still feel in control because at the end of the day, fear is my bitch."[75] She decided to make those words part of her clothing line and had her brother, who owns a T-shirt printing company, put "Fear is my bitch" on T-shirts.[76] Even with all that was thrown at the disabled entrepreneurs on *Born for Business* as the pandemic happened, they all embodied the resilience found within many disabled people, who move forward even when catastrophe strikes. Allen summarized it well in episode 10: "Life is going to happen. I can't be afraid."[77]

Born for Business also illustrates the community that people with both visible and nonvisible disabilities can build, as they discussed aspects of their businesses with each other. Because he owns concert venues and clubs, cast members Chris Triebes collaborates with Qiana Allen on a livestreamed fashion show of Allen's clothing at his club.[78] That episode is aptly named, "Think outside the box," which is what disabled people do daily to navigate an inaccessible and ableist world. Now that social media exists, community building and support of each other is a prominent feature especially for people with chronic illnesses and nonvisible disabilities. London School of Economics ethnographer Elena Gonzalez-Polledo investigated how communities of chronically ill people, especially those in pain, use Instagram and Tumblr. In addition, Gonzalez-Polledo says that social networks “offer opportunities for people without pain to better understand the experience of having pain.”[79] She explains that these platforms give chronically ill people a way to connect with others who have similar pain experiences and can grasp what their lives with chronic illnesses are like.[80] People with nonvisible disabilities understand how “Spoon Theory” governs each other’s lives. Coined in 2003 by writer/blogger/speaker/patient advocate Christine Miserandino, who has lupus, Spoon Theory is a concept that explains the limited physical or mental energy someone with chronic illness may have to get a day’s tasks done, in contrast to someone without illnesses or disabilities.[81] Many people with nonvisible disabilities/chronic illnesses call themselves “spoonies,” and Spoon Theory is discussed more recently in Disability Studies, the medical community, and even popular culture, as when MTV interviewed Miserandino about singer/actor Selena Gomez’ lupus diagnosis in 2015. Miserandino welcomed Gomez into the spoonie community:

> After I heard the news about Selena, I just wanted to reach out to her and hug her. We all make choices whether to reveal our lupus or not. Selfishly I’m thankful she did. ... By sharing her truth, she’s brought a spotlight to a very unknown illness. This will help millions of new patients get diagnosed faster and help current patients feel so not alone. I hope she knows she has a ‘spoonie’ friend to talk to ... if she does need one, I am right here.[82]

In recent times, #spoonie trends on Instagram and TikTok with posts, comments, and videos explaining what it is like to plan daily lives around limited energy or brain fog. But they also feel camaraderie and comfort when interacting with other spoonies online. *Stylist* magazine in the UK asked women with chronic health conditions how an understanding of Spoon Theory helps them. One comments

> I have lupus and being seen and understood without having to explain myself is a comforting thing. In the community it doesn’t matter what illness people have, there’s no competition, just pure sympathy and an understanding that we all have limited spoons each day and how draining that is. Mollie[83]

Scottish graphic designer and disability advocate Jenny McGibbon[84] whose online presence can be found at This Thing They Call Recovery uses her art to create spoonie memes, images, and videos for her posts on social media. She is autistic and has Myalgic Encephalomyelitis and Gastroschisis.[85] Her

TikTok video posted on Instagram on February 6, 2023 clearly illustrates what happens when her conditions flare:

> Video description: Jenny sits on her bed looking exasperated by all the layered sounds. Text on screen reads: when all the symptoms are flaring at once. The clip then cuts to silence, Jenny points to her black tshirt that says 'everything hurts and I feel like death'. The audio then says 'see ya'. Tshirt from Jenny's own range.[86]

Her followers' comments illustrate how other people with chronic illnesses feel seen and can relate to her day with multiple symptoms, and they sweetly comment on her cute haircut and earrings as well. Via many social media platforms and television shows, people with nonvisible disabilities are finding each other and creating positive support networks.

Crazy ex-girlfriend

Singer/actor/comedian/writer Rachel Bloom, who has been open about her diagnoses of anxiety and depression,[87] radically changed the representation of people with mental health disabilities with her romantic musical drama comedy show *Crazy Ex-Girlfriend* (2015–2019)[88] on America's CW cable network. The award-winning show was praised by people with a mental health diagnosis, Disability Studies scholars, and the U.S. film and television industry. The CW network appeared to see its value because it was one of the lowest rated shows that it has renewed.[89] Over the course of its 62 episodes over four seasons, the show created a nuanced portrayal of attorney Rebecca Bunch (played by Rachel Bloom) as a highly intelligent and competent attorney who appeared to have a mental illness that shaped her many times unconventional behaviors, but the mental illness was not identified in the first two seasons. In the pilot episode, Rebecca threw away her medications for a mental illness with the implication that now that she was reunited with her musical theatre camp crush, Josh Chan, her mental health issues would subside. Each episode contained many songs that served as a kind of inner dialogue from Rebecca about what was happening to her. By the end of season 2, everything unraveled when Josh and all her friends learned of her arson charges from a previous romantic relationship years before that led to her stay in a psychiatric facility. At the beginning of season 3, Rebecca tries to commit suicide and her friends, including Josh, rally around her now that they know her behaviors were part of her illness. After singing a power ballad called "A Diagnosis"[90] in season 3, in which she is thrilled to find her community of other people with her mental illness, Rebecca finally gets an accurate diagnosis of borderline personality disorder (BPD). But unlike film and television's typical representation of mental illness, there is no cure or quick fix for Rebecca's mental illness, but there is a journey of hope, support, and resilience throughout the final fourth season. And viewers connected with the frank and authentic storylines coming from a creator who experienced her own mental health diagnoses. A writer who has experienced 20 years of depression and anxiety said in 2018 that "not only is the show relatable for those dealing with mental health issues, it's also helping those who don't understand what that experience is really like."[91]

When the show first appeared, a few viewers refused to watch because they disliked its name and use of the word "crazy." Bloom told MTV in 2015 that the show reclaimed the word in a way that it could be empowering and feminist for someone with a mental illness:

> It's so funny, because people have been like, 'Oh, crazy, that's a patriarchal term.' That's the whole reason we called the show that — from the beginning we were seeing it from such a feminist, and from Rebecca's, point of view. We didn't actually think people wouldn't understand at first that it was a dark, romantic comedy that deconstructed that very term, and that's just because from the beginning the show has always been about deconstructing stereotypes.[92]

Bloom and co-creator Aline Brosh-McKenna planned to honor the journey of a character with a mental illness because it came from their own experiences with mental health disabilities. Rebecca Bunch embodied Bloom's recognition of her own mental health diagnoses since childhood.

> She's a version of myself, she's a version of [co-creator] Aline [Brosh McKenna], she's people we've known. A lot of this stuff, mental health and depression — and lot of [other] taboo topics — if we just face them head on they lose their power... I've dealt with anxiety and depression, and a lot of my friends have. That's why I write about it a lot, because if I write about it and I make fun of it and I get ahead of it, then I conquer my fear.[93]

Getting into musical theater as a middle schooler and years in therapy helped Bloom embrace her OCD, anxiety, and depression as part of who she is. In her 2020 memoir, *I Want to Be Where the Normal People Are*, Bloom says she struggled with the idea of "normal" even as child, writing when she was 12 that "if no one is sure what it is, then why are people harshly judged by its qualifications every single tedious day?"[94]

Even before her book, Bloom discussed her anxiety openly in interviews with the media and says although she had been working with a therapist, she had even more anxiety as she developed *Crazy Ex-Girlfriend* and sought medical help from a psychiatrist who said she also has depression and put her on a low-dose antidepressant. "There's a stereotype (I had believed) that antidepressants numb you out; that didn't happen to me," she says. She adds that now that she is open about her anxiety and depression, her psychiatrist, her husband, and her *Crazy Ex-Girlfriend* co-creator can give her emotional support.[95] Bloom has also added meditation into her life and says that helps her deal with her anxiety spirals, as she calls them. She has become involved with some mental health activism to destigmatize treatment, as when she discussed her anxiety and depression in a video for the Child Mind Institute in 2017. She explains how being open about her mental health and writing about it helps her

> Once I started writing about the darkest parts of myself, I found that other people really related to it and what that meant was – sometimes the worst parts of having anxiety or depression or those dark moments are feeling like you are the only person who has this and you are weird and you are broken and why don't you just snap out of it? …If we could all just talk about it, we could end the stigma because a lot of us are going through the same thing. For me, talking about it and sharing helps expel some of the bad poison. The idea that there should be any stigma around treatment or being depressed or anxious kind of labels you with a scarlet letter is kind of nonsense, and openness and normalizing it helps everyone.[96]

Antidepressants get a dedicated song in the show, "Anti-Depressants Are So Not A Big Deal," when Rebecca Bunch's therapist Dr. Akopian (played by Broadway and television star Charlene "Michael" Heard) and a dancing and singing chorus of others on antidepressants explain in song their ubiquity in American society:

> Some cry that in the past, we didn't medicate everyone
> Cool, witch trials and the Crusades sounded like so much fun
> Anti-depressants are so common
> That taking them is all we have in common[97]

That song about antidepressants won an Emmy[98] for Best Original Music and Lyrics in 2019 for Bloom, songwriter Jack Dolgen, who also takes antidepressants,[99] and composer Adam Schlesinger.

Bloom and her co-creator Brosh McKenna knew the character of Rebecca Bunch was on a journey with a mental illness and consulted mental health experts who helped them understand the character's BPD diagnosis. In one scene, her therapist reads the checklist for BPD to Rebecca, and she flashes back to scenes in past episodes that confirm her behaviors are on the checklist.[100] BPD is an extremely stigmatized and misunderstood mental illness that even some psychiatrists won't treat, so Brosh McKenna says they were careful in their representation of the BPD diagnosis

> We wanted to show the human aspect of somebody who thinks their diagnosis is going to be some sort of badge of honour, and then it's something that she really doesn't like. I think one thing that's important

> to note is no diagnosis is a perfect diagnosis. It's a bit imprecise and there are many schools of thought on BPD, but we try to dial in what we felt like was accurate for her. What's amazing about that flashback sequence where you see all those things that she's done [is] we have 10 [examples we could have used] for each of them.[101]

Brosh McKenna says they wanted to show Rebecca dealing with BPD in an authentic way because BPD is a group of behaviors that are difficult to treat. But even with the character's struggle to accept that she has BPD, Rebecca is shown as empowered by finally having information about her mental illness. Brosh McKenna says, "she now has a name for this whole host of behaviours, but the host of behaviours are so deeply rooted in her that she's going to continue to struggle with it, but struggle with more information."[102]

Viewers of the show with BPD applauded the authentic storyline. Victoria Taylor, who has BPD, began watching the show once she learned of the character's diagnosis. She found a number of similarities between herself and Rebecca: "Like her, I struggled through many years of mental health problems before realizing I had BPD, and it was my diagnosis that led to the start of my recovery."[103] Because she knew of Rebecca's diagnosis from the beginning, Taylor says that she noticed Rebecca's BPD behaviors throughout the series. One episode resonated with her particularly:

> The standout line for me in the show, the one that really resonated deeply with me, came quite early on – in Season 1, Episode 5, 'Josh and I Are Good People!' Rebecca tells Stacy Whitefeather, the ex-wife of her boss Darryl (who she is trying to help with his custody battle to prove she is a good person): "Because of that lack of paternal validation, I always seek outside validation from others." When she said this, it made an immediate impact on me. It was like someone had reached into my head and summarized my life in one sentence.[104]

Charlie Martina, who has BPD, also saw their life in the Rebecca character:

> Even before Rebecca had been officially diagnosed, I related to her on a level that I never had to a fictional character. Her dad left when she was young, she was up and down like a yoyo, and she acted incredibly impulsively – just like me![105]

Martina explains that the show was significant because it gave accurate information about BPD while serving to destigmatize a mental illness that few understand. Martina says:

> By Season Three, you start to realise that she needs real help and that (spoiler alert!) seeking out romance is not benefiting her. This is where the real growth happens; her friends find out her deepest secret and,

> instead of hating her for it, try and support her in getting some help. She agrees, and eventually receives a diagnosis of BPD. Things that didn't add up before start to make sense, and she begins the difficult task of working on herself. I was touched – I felt as though she and I were uncovering our struggle with BPD together, side by side.
>
> Whilst I think that mental health diagnoses can be problematic, when I received mine (alongside Rebecca receiving hers), I felt more validated and understood than ever before. This is a common, tough, and even life-threatening condition that not enough people know about. *Crazy Ex-Girlfriend* gives an honest, non-judgemental, and stigma-free portrayal of BPD from Rebecca's perspective. I applaud the show for telling the honest truth: both that she has reasons to act the way she does and that her behaviour is unacceptable at times. She's not manipulative or attention-seeking, she is struggling with a mental health condition that millions of people struggle with, and she's doing a fantastic job.[106]

British TV producer and comedy writer Adeel Amini, who has BPD, says *Crazy Ex-Girlfriend* gave him a reference for his friends who wanted to know more about his diagnosis. Even with treatment, BPD can sometimes seem like an emotional rollercoaster ride, Amini says. "Living with BPD means trying to regulate your emotional polygraph, which is infinitely more sensitive than a neurotypical human," he explains. Amini calls his BPD diagnosis "a bright learning experience," but he understands that it is an ongoing condition that he will always have to navigate, just like Rebecca Bunch.[107]

Crazy Ex-Girlfriend's viewers with BPD and other mental illnesses or nonvisible disabilities are validating the show's "crip" narrative. Journalist Laura Dorwart, whose Ph.D. dissertation looked at narratives about mental health in the media, says "Bunch became one of TV's most endearing yet realistic characters with a known psychological disorder."[108]

Dorwart writes that the show critiqued ableist and sexist media tropes about mental illness.

> By probing the stereotypes about how women are expected to experience and express symptoms of mental illness, Rachel Bloom's show forces viewers to confront their own preconceived notions about the lasting cultural figure of 'the crazy ex-girlfriend' and re-examine our expectations of mentally ill characters,

Dorwart says.[109] Disability studies and medical rhetoric scholar Caitlin E. Ray writes in the 2021 book *Perspectives on Crazy Ex-Girlfriend, Nuanced Post-Network Television* that the nonlinear plot, the cripped perspectives of Rebecca, the musical numbers shifting time, and the rejection of traditional negative stereotypes of mental illness come together for a true cripping of the narrative in the show.[110] One of the musical numbers, "The End of the

Movie," is a meta-critique of both the Rebecca character's life and film and television tropes that *Crazy Ex-Girlfriend* is rebuffing.

> Life doesn't make narrative sense…
> Because life is a gradual series of revelations
> That occur over a period of time
> Some things might happen that seem connected
> But there's not always a reason or rhyme
> People aren't characters. They're complicated
> And their choices don't always make sense[111]

Sung by Josh Groban, the song explores Rebecca's realization that she was trying to live in a romantic comedy-style movie, when, in fact, her life is framed by an undiagnosed mental illness. At the meta level, the song is critiquing how viewers also use film and television to escape their own lives but want their lives to have neat uncomplicated resolutions like in the movies. Ray says songs like these in Season 3 "highlight the chaos that Rebecca feels,"[112] and they illustrate the authentic way that *Crazy Ex-Girlfriend* represents mental illness. This authentic depiction of mental illness "is pivotal in how the show resists the typical resolution or linearity that the audience may want in a story and instead uses music to explore the chaotic way ways that mental illness defies those expected narratives."[113] There is no resolution or "cure" of Rebecca's BPD: "The show depicts Rebecca's recovery as the slow, imperfect process it often is. This accurately represents the process of diagnosis, prognosis, and treatment as halting, full of stops and starts."[114] At the end of the show, Rebecca Bunch forges a new path as she lives her life with BPD – "she writes songs to make sense of her life and help her make decisions."[115] Ray says this resolution of Rebecca's story with self-reflection, supportive friends, and being open about her experiences with a mental illness signifies the cripped narrative of *Crazy Ex-Girlfriend*. Ray explains:

> Her cripped perspective is valued and honoured. She does not *have* to only work through her experiences through song (as she now has a valuable support system and people who love her), but she *should* because her voice in the world is valuable. The series finale thereby self-reflexively comments on how the cripped narrative offered by the show has resonated with many viewers who feel that they too are alone and off-time.[116]

Ray says Rebecca learns she is loved and supported because of her value as a person and thus the character models that viewers with mental illness are also valued.

Rachel Bloom discovered the show's impact in people's lives when she and the cast began doing live shows in 2018 of some of the 150+ songs[117] from *Crazy Ex-Girlfriend*. In her memoir, Bloom said the songs she most feared writing for the show like "Stupid Bitch" and "A Diagnosis" resonated with many people.

> Then we started doing live shows and I saw that the very songs I'd been the most scared to write were the songs that people connected with most….No matter what they looked like, they all had one thing in common: They saw themselves as outsiders. And they were kind, smart, funny, generous, and fascinating.[118]

Bloom says the support from fans transformed her because she no longer "wants to be where the normal people are" and is finding happiness as an outsider.

Conclusions

As Josh Groban sings in the Crazy Ex-Girlfriend song, "The End of the Movie," "Life doesn't make narrative sense…Because life is a gradual series of revelations that occur over a period of time," and that is a good metaphor for the journey of many people with nonvisible disabilities/chronic illnesses. Their conditions may flare and calm, and they may come to a better understanding of what can give them comfort and a feeling of well-being. But it is the connections made online with other disabled people and the accurate representations of their nonvisible disabilities in popular culture that truly begin to assist them in coping with the ableist and inaccessible world all around them.

As Disability Studies scholar Susan G. Cumings explains, giving and receiving information online about their nonvisible disabilities empowers both creators and audiences.[119] They are opening up their lives and experiences in online spaces and that builds resilience. Cumings says, "These disability activists, harnessing the paradox of 'making the invisible visible,' shake up habits of perception and judgment and encourage others, through online forums and hashtag activism, to join in this crowdsourced disability pedagogy and activism."[120] Online social spaces and the disability community's newer ability to communicate with media creators at all levels of the entertainment industry remind that famed deaf-blind advocate Helen Keller called on all people to join together to accomplish social good. As she said, "Alone we can do so little; together we can do so much."[121]

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