



DISABILITY AND THE CIRCUS

Rachel Adams

The bus runs on used cooking oil that has to be scavenged from restaurant dumpsters. It keeps breaking down, until finally it dies completely. There is garbage everywhere and arguments erupt over who should clean up. The giant tries to talk and people keep interrupting him. The Elephant Man has been left behind. The clown has lost his dog, who is also his best friend. The Human Tripod has a vicious hangover and spends all day lying on the couch. The giant gets fed up and catches a plane back to Oregon. Lobster Girl pulls a black hair from her chin and worries that she's getting fat. These scenes from a film called *The Last American Freak Show* illustrate how far we've come from the romantic ideal of running away to join the circus. It is 2006, and the performers in *The 999 Eyes of Endless Dream* have missed the heyday of the freak show by about one hundred years (fig. 17.1).

For six weeks, filmmaker Richard Butchins accompanied this traveling freak show as it drove from

Oregon to Austin, stopping to perform at bars, nightclubs, parties, and a wedding along the way. His documentary *The Last American Freak Show* is a road narrative in the vein of Jack Kerouac's *On the Road* or Ken Kesey's *The Electric Kool-Aid Acid Test* in that it details the allure and the disillusionment of vehicular travel across the American continent. Like these precursors, it recognizes the road as a place where rebels and outcasts seek escape from the pressures of mainstream society. It appreciates the impulse toward nonconformity, while also recognizing the loneliness and discomfort that come with self-imposed marginality. What distinguishes Butchins's story is that the majority of his travelers have significant congenital disabilities. They are "freaks" not only in their rejection of social norms but because of their deviance from bodily norms. As in Katherine Dunn's 1986 road novel *Geek Love*, the performers in *The 999 Eyes* make a living by exhibiting themselves, flaunting their differences rather than attempting to hide or normalize them. But this isn't fiction; it's real

◀ Detail from fig. 17.1 (AC-273) Edward J. Kelty, Congress of Freaks at Ringling Brothers and Barnum & Bailey Combined Circus, 1924. Photograph, The Collection of the John and Mable Ringling Museum of Art Tibbals Digital Collection, ht0004824



life. Some use wheelchairs or prostheses, and some require consistent medical attention.¹ *The Last American Freak Show* asks why people with disabilities would choose to exhibit themselves as freaks in post-Americans with Disabilities Act (ADA) America, and what it meant for Butchins—who is himself disabled—to undertake this journey.

The Last American Freak Show was controversial. In 2008 it was banned from the BAFTA (British Academy of Film and Television Arts) Disability Arts Film Festival after the head of events declared that “the aesthetic of the film was wrong, that it was too explicit, raised too many questions and was too demanding for the event in question.”² Butchins has never been able to find a distributor. And yet, the film has screened to considerable acclaim at festivals around the world, where it has received enthusiastic reviews. What makes *The Last American Freak Show* provocative is that, unlike other recent documentaries about contemporary circus life such as *American Carny: True Tales from the Circus Sideshow* (Nick

Basile, 2008), *Sideshow: Alive on the Inside* (Lynne Dougherty, 2003), or *Sideshow: The New Sideshow* (Tim Miller, 2003), this film bluntly tackles questions about the meaning of disability at the freak show. Given that people with disabilities were often cruelly exploited by circus managers and showmen, it questions what place people with disabilities might occupy within the modern circus and what their performances can tell us about being disabled in twenty-first century America.

Disability and the Freak Show

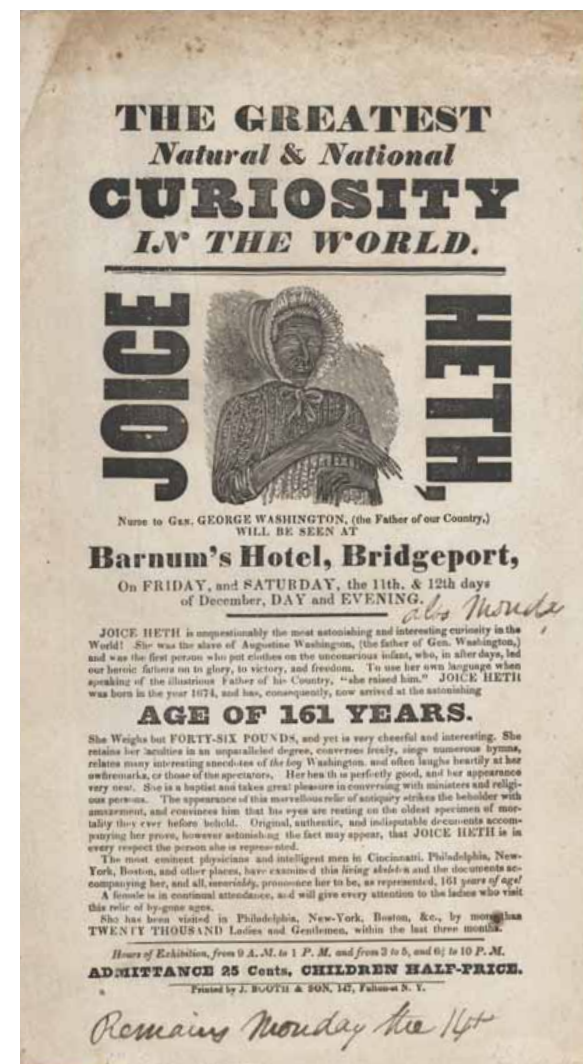
The circus has long been a gathering place for people with exceptional talents. It was P. T. Barnum who first realized the potential for combining the exhibition of human oddities with more traditional circus fare such as trained animals, clowns, acrobats, and dancers.³ Barnum got his start by as a showman by capitalizing on disability. He purchased an elderly

▲ Fig. 17.1 (AC-273) Edward J. Kelty, Congress of Freaks at Ringling Brothers and Barnum & Bailey Combined Circus, 1924. Photograph. The Collection of the John and Mable Ringling Museum of Art Tibbals Digital Collection, ht0004824

black woman named Joice Heth, whom he advertised as the 161-year-old mammy of George Washington (fig. 17.2). Heth was not congenitally disabled, but her body was bent and twisted with age and decades of hard work. Under Barnum’s management, this unremarkable old woman became a sensation. When public interest in Heth waned, he rekindled it by spreading the rumor that she was not a living person, but an automaton. Barnum exhibited Heth until the day she died, when he garnered further publicity by arranging for a public autopsy to verify her age.⁴ Over the course of his career, Barnum was responsible for introducing some of the most famous human curiosities of his time: the conjoined twins Chang and Eng; the diminutive Tom Thumb; Lavinia Warren, and Commodore Nutt; William Henry Johnson, the “What Is It?”; the giants Anna Swan and Colonel Routh Goshen; Maximo and Bartola, the Aztec children; and Charles Tripp, the no-armed boy (fig. 17.3).⁵ These performers’ unusual bodies provided the raw material for the creation of freaks. Barnum’s genius lay in understanding how to use narrative and props to turn bodily impairment into a spectacle people would pay to see. He soon had many imitators, and the freak show became a regular feature of the American circus.

Sometimes human oddities were incorporated into the circus ring, but more commonly they were part of a sideshow (fig. 17.4). Located in its own tent and requiring an extra fee for admission, the sideshow was among the most popular and profitable attractions at the circus. Freaks were defined by bodily features spectacular enough to make audiences want to stare, however the sideshow always contained an element of performance. Costumes, props, the showcasing of unique abilities and talents, and extensive advertising turned people with disabilities into freaks. Not every freak was dis-

abled. Sideshows also included people with extremely long hair or nails, tattoos, and women in pants, as well as non-Western people, and those with unusual talents like sword swallowing, fire eating, and contorting. Sideshow acts could also be inspired by current events. “I am speaking of America—the land of real humor, of ingenuity, or resource,” reported journalist William Fitzgerald in 1897, “When some important political or other event agitates that great country, topical sideshows spring up with amazing promptness.”⁶ Thus, at various points in the nineteenth century, suffragettes, Philippinos, Native American chiefs, and Africans were exhibited as freaks.



► Fig. 17.2 (AC-115) “Joice Heth, The Greatest & Natural Curiosity in the World,” 1835. Handbill, printed by J. Booth & Son, New York Somers Historical Society



Born freaks—those with congenital disabilities—were the aristocrats of the sideshow world. The more unusual their bodies, the better chance they had to control their salaries and working conditions. Chang and Eng Bunker, the famous conjoined twins, set their own terms when they toured with P. T. Barnum. They made enough money to settle in North Carolina, where they married sisters and fathered twenty-one children.⁷ Few freaks were this fortunate. The conjoined twins Daisy and Violet Hilton never achieved the enduring success of their precursors. After a lonely and abusive childhood, they seemed poised to embark on a glamorous career as film and vaudeville stars (*fig. 17.5*). But they were exploited by managers and agents, who abandoned them once their public appeal declined. They ended

their lives in obscurity, working at a grocery store and dying alone in their small apartment.⁸ Joseph Merrick, who was exhibited as The Elephant Man in the late nineteenth century, fared no better. After touring Europe, he was robbed and abandoned by his manager. So severe were his disabilities that it was dangerous for him to appear in public alone (*fig. 17.6*). He finally made his way to London, where he was rescued by Dr. Frederick Treves. He spent the rest of his life in Treves's London hospital, where he died of asphyxia while sleeping.⁹ The life of Julia Pastrana, The Bearded and Hairy Lady, was also filled with hardship and betrayal (*fig. 17.7*). Her parents sold her to a showman who taught her to dance and play music, and eventually married her. She gave birth to a baby with features much like her own, who lived for only two days. Pastrana died soon after from complications of childbirth. But that was not the end of her career. After having both wife and baby mummified, Pastrana's husband continued to exhibit them in a glass case.¹⁰

In the era before the welfare state, many people with severe disabilities turned to freak shows for economic support. Some parents sold children born with disabilities to showmen, having no other means to care for them. American cities passed “ugly laws” banning persons with “unsightly or disgusting” disabilities from appearing in public.¹¹ These ordinances made the possibility of gainful employment, or even begging, more difficult. A souvenir carte-de-visite sold at a freak show makes the case for a man whose hands were disabled after being struck by lightning at age six: “He would gladly undertake any labor that would furnish him a livelihood, but how can he? Yielding, therefore, to the suggestions of friends he offers for sale his photograph, hoping that the small profit derived therefrom will contribute to his maintenance and support.”¹² His plea represents exhibi-

▲ *Fig. 17.3* (AC-116) P. T. Barnum and General Tom Thumb (Charles S. Stratton), ca. 1850. Photograph. © Bettmann/Corbis

tionism as a form of work that allows a man who has no other means of income to earn a living. It allows spectators to conceive of staring as a charitable act. Any squeamishness they might feel about gawking can be assuaged by buying a photo.

Freak shows could provide a livelihood for people with disabilities, but they were also a source of community, a place where their differences were accepted and even affirmed. While the show was on the road, the circus or carnival was a total environment where work and life ran seamlessly into one

another. When not performing, circus folk were eating, sleeping, and spending their spare time together, creating a subculture insulated from the outside world with its own vocabulary, customs, and values. Onstage, freak shows exploited the continuity between life and performance by having people with disabilities perform everyday tasks: a person with no arms and legs lighting a cigarette; conjoined twins dancing, singing, and turning cartwheels; Lobster Boy tying knots. A familiar spectacle was the wedding of two unlikely performers, such as a midget



▲ *Fig. 17.4* (AC-357) Frederick Whitman Glasier Side show banner and entrance, Zip, the Pinhead (William Henry Johnson) playing violin at center, 1906. Photograph. The Collection of the John and Mable Ringling Museum of Art Archives, Glasier 0033

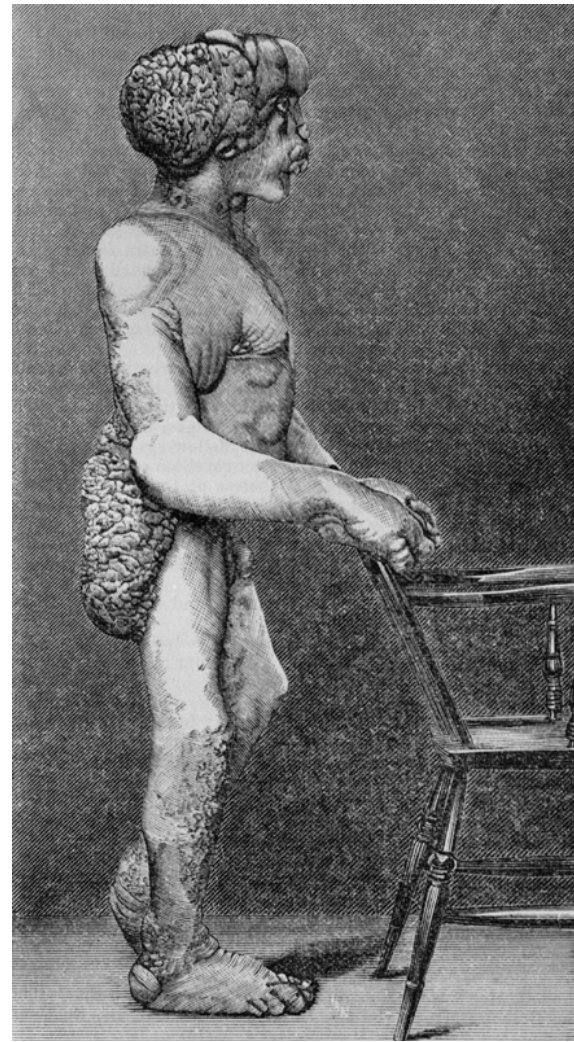
and a giant or a fat lady and a human skeleton, who then could be advertised as “The World’s Strangest Couple.” Many of these weddings were simple publicity stunts, however, some disabled performers—such as Jeanie The Half-Girl and the giant Al Tomaini, and Percilla The Monkey Girl and Emmitt Bejano, The Aligator-Skinned Man—also found enduring love backstage at the sideshow, where unusual bodies were the norm (figs. 17.8, 17.9).¹³ Both of these couples met while touring with the freak show, eventually retiring and remaining together to the end of their lives. Those who did not find romance often appreciated the friendship and camaraderie of circus life. Beginning in the 1940s, many circus performers spent their winters in Gibsonton, Florida (aka Showtown USA), where the fire chief was a giant, the sheriff a dwarf, and unique zoning laws allowed them to keep elephants and carnival rides on their front lawns.¹⁴

With the rise of scientific understandings of disability, freak shows became less socially acceptable. Advances in medical knowledge and treatment made it possible to cure some conditions that once would have led to disabilities. Doctors began to provide scientific reasons for disabling conditions, framing them as pathology rather than sources of wonder. Increasingly, public sentiment turned away from the freak show, which had never been a completely respectable form of entertainment in the first place. It



▲ Fig. 17.5 (AC-119) Violet and Daisy Hilton, upon their return from performing in England, October 6, 1933. Photograph. © Bettmann/Corbis

▲ Fig. 17.6 (AC-117) Joseph Merrick, the Elephant Man, illustrating the deformities caused by neurofibromatosis, ca. 1885. Photograph. © Corbis



was no longer tolerable for people with disabilities to exhibit themselves for paying customers to gawk at. Rather, it was believed that they should receive treatment, and the incurable should be concealed from view in hospitals and institutions. In later decades, similar complaints would be leveled about the exploitation of trained animals.¹⁵ As a result, many of today’s circuses—such as Cirque du Soleil, Jim Rose Circus, the Bindlestiff Family Circus, Circus Smirkus, The Flying High Circus, and Circus Chimera—consist entirely of able-bodied performers, featuring no animals or people with disabilities.

Although changing times sent freak shows into decline, they never disappeared entirely.¹⁶ Instead,

they moved to the social margins, where they continued to court less prosperous and respectable clientele. By the mid-twentieth century, freak shows were no longer part of the circus, surviving instead at county fairs, traveling carnivals, and New York’s Times Square and Coney Island. However, in the last twenty years live freak shows have seen something of a revival among young hipsters and bohemians, who have brought them back under the aegis of circus performance. In *Freaks and Fire*, J. Dee Hill claims that the contemporary circus functions along the lines of a tribe, attracting the same populations as alternative cultural gatherings like the Burning Man festival and Rainbow Family.¹⁷ Participants tend to be young and white, with backgrounds in dance, theater, music, and fine arts. Whereas once the families of circus folk passed their acts from one generation to the next, few participants in the contemporary sideshow are connected to earlier generations of circus performers.

Most of what passes as a freak show today is vaudeville-style performance involving musicians, artists, and people with unusual abilities such as acrobatics and contortion, fire eating, sword swallowing, pounding nails into various parts of the body, walking on glass or burning coals, and escaping. It is rare to find people with congenital disabilities in troupes such as The Jim Rose Circus, The Bindlestiff Family Circus, Circus Contraption, and Yard Dogs Road Show, where often the performers are extremely fit and able-bodied (fig. 17.10). When people with disabilities are included, there is less of a divide between the born and the made, since they are also performing. For example, Jennifer Miller is a woman with a beard who has worked with the Bindlestiffs, at Coney Island, and her own troupe, Circus Amok. Some venues showcase her beard more than others, however she is also a skilled

acrobat who dances, chews light bulbs, and delivers monologues that combine comedy and social criticism (fig. 17.11). Tony Torres was a dwarf who exhibited himself at Coney Island’s Sideshows by the Seashore. But he did so in the guise of Koko the Killer Clown, an act that involved wearing heavy makeup, dancing, cracking jokes, and making balloon animals. Born freaks are thus no longer the sideshow’s elite, nor are they considered necessary to its success since the contemporary circus relies



▲ Fig. 17.7 (AC-118) Miss Julia Pastrana. Lithograph with text in French, English, and German. Harvard Theatre Collection, Houghton Library, Harvard University



almost entirely on working acts, and performers with sensational talents, skills, or bodily adornments such as piercing, dreadlocks, and tattoos.

What makes The 999 Eyes of Endless Dream stand out among contemporary freak shows is that so many of its performers are disabled, and disability is at the forefront of their acts: a dwarf chews on light bulbs and walks on crushed glass; a woman with no legs turns cartwheels and sings; the Lobster Girl ties knots with her unusual hands; Lobster Boy does magic; and all of them tell stories, both funny and sad, about living with a disability in America (fig. 17.12). In *The Last American Freak Show* filmmaker Richard Butchins explores how The 999 Eyes recalls and re-scripts the traditional place of disability within the freak show. He asks what it means for a contemporary person with a disability to exhibit herself as a freak, and what he, as a person who is himself disabled, learns from his encounter with the freak show.

▲ Fig. 17.8 (AC-120) (above) Bernice “Jeanie” nee Smith and Al Tomaini, ca. 1950–55. Photograph. Circus World Museum, CWI-2298



Performing Disability

Early in *The Last American Freak Show*, Butchins describes the genre as “a truly American art form.” In making this claim, he alludes to the fact that, although circuses and freak shows have a long history in Europe and other parts of the world, it was the American P. T. Barnum who first recognized their potential as a mode of commercialized mass entertainment, developing them into a form that has become known throughout the world. Given that the freak show came into its own in the United States, it makes sense that Butchins would travel there to investigate how it is faring in the new millennium. As the British Butchins observes the troupe, he participates in a long-standing European fascination with America that can be traced back to the writings of Hector St. John de Crèvecoeur, Alexis de Tocqueville, Charles Dickens, and many others. During their tour,

▲ Fig. 17.9 (AC-121) (right) Percilla née Roman and Emmitt Bejano, ca. 1940s. Photograph. Circus World Museum, CWI-2297

The 999 Eyes drive from Oregon to Texas, stopping to perform in small cities and towns along the west coast and southwestern U.S. As he films the troupe, Butchins also documents the American landscape. Like his characters, his establishing shots also tend to capture places that are unsightly and marginal: highways, roadsides, parking lots and rest stops, motels, diners, dumpsters, and bars.

Promoting itself as “the last genuine traveling freak show in the United States,” The 999 Eyes claims to be bringing the freak show back from the past, repackaged for the twenty-first century. Much as it recalls its precursors, this freak show is also decidedly modern (fig. 17.13). When we first meet them, many of the performers travel in a 1988 International Bluebird school bus owned by Laurent Martin, aka Lowrent the clown. The motor has been converted to run on used vegetable oil scavenged from the back of restaurants and anywhere else it can be found. Butchins uses infrared lights to film several late-night scenes in which the performers—still dressed from the evening’s show—search dumpsters for fuel. In his blog, he describes oil as an abundant national resource “which in the USA is everywhere because they fry everything they eat.” Whereas Barnum was the first to transport his circus by train, The 999 Eyes are pioneers in the technology of enviofuel. Taking advantage of others’ waste, the converted bus also provides a modern twist on the classic circus caravan, reflecting a contemporary awareness about the environmental impact of burning fossil fuel. In terms of personal style, the freaks are modern as well, adorned with dreadlocks, multicolored hair, piercings, tattoos, and heavy makeup. While technology is not a significant aspect of their performances, where a low-budget homemade aesthetic prevails, it is central to life offstage, where the troupe members commu-

► Fig. 17.10 (AC-122) Roy Volkmann. Bindlestiff Cirkus Magic Hat Troupe, 2007. Photograph. ©Bindlestiff Family Cirkus

unicate by email, quarrel over cell phone minutes, fly in by plane, shop at the mall, and watch CNN in their motel rooms.

While The 999 Eyes enjoy the conveniences of the modern world, the troupe also calls itself “the last” of its kind, a phrase that gestures backward to a waning tradition. It may be closer to its nineteenth-century forerunners than any other contemporary sideshow in that it privileges the “born freak” over all other performers. Indeed, its claim to distinction is that it includes more born freaks than its competitors. During the 2006 tour, these include H. E. A. Burns, The Lobster Girl; Ken, The Elephant Man; a dwarf named Dierdre (aka Dame Demure, The Dancing Dwarf); Jackie, The Human Tripod; Erik, The Gentle Giant; and Jason Black, The Lobster Boy. On their website, the group defines a freak as “a human oddity that has chosen to share, celebrate and exploit his/her own genetic anomaly through performance.”¹⁸ Here they uphold the carnies’ traditional reverence for born freaks, while adding a modern recognition of genetics as the cause of some of their disabilities.





The performers' online biographies are filled with exaggeration and pure humbug, knowingly evoking the rhetorical tradition of sideshow pamphlets. For example, it presents the story of Ken (aka The Elephant Man or Pegleg) as "an inspirational triumph over adversity":

Born in 1895, inflicted with the genetic disorder NF to the point of having one leg removed, Pegleg traveled the freakshow circuit. He stayed on until 1935 when scientists, whose goal it was to kill the freakshow for social control, stole him from the midway to experiment on and study him to prove that his condition was that of a sick human and not of a Fabulous Freak . . . because funding for the project was cut they decided to freeze him until more funds could be obtained. The funding never came and Poor Pegleg was forgotten.

Until one day a kindly showman snuck into the

basement of a medical anomalies laboratory. Her initial goal was to obtain a two-headed baby for her show, but it was there that she then discovered the man frozen. After defrosting Pegleg she set out to help him in his mission of revenge on the scientists who are still trying to destroy the freakshow Museum of Mutantstrosities by institutionalizing, exploiting and abusing freaks for medical answers and experimentation.

Ken's biography leaves no question about its veracity. However, its tale of evil scientists and kind show people alludes to an underlying historical truth, the long-standing conflict between the freak show's investment in wonder and sensation (Fabulous Freak), and medicalized understandings of disability (a sick human). Show people have long been disdainful of the scientists' cultural prestige at the same time that they sought to appropriate it by seeking experts who could validate the freak's authenticity, and by calling themselves doctors, professors, and scientists. The 999 Eyes website expresses a similar ambivalence toward medical professionals in that it denigrates the treatment of people with disabilities as specimens to be studied and classified while at the same time giving Ken's condition a medical name and providing a link to the Wikipedia article on neurofibromatosis.

As was true of previous generations, the performers in *The Last American Freak Show* see The 999 Eyes as a source of community and affirmative self-expression. Butchins explains that the freak show gives them the means to come "out of the institution and the welfare office," where people with disabilities have been relegated for generations. In the wake of the Americans with Disabilities Act, opportunities for inclusion in schools and the work-

▲ Fig. 17.11 (AC-123) Andrew Lichtenstein. Jennifer Miller denouncing Mayor Giuliani's policies in one of her circus shows, July 1999. Photograph. Corbis, © Andrew Lichtenstein / Sygma / Corbis

place have increased. But it is still true that most people with disabilities are poor and have difficulty finding employment. They continue to face social prejudice, challenges of transportation and access, and discrimination in hiring.¹⁹ The performers in Butchins's film resist becoming a part of the disability underclass by seizing control of their own representation. A disabled body is a hypervisible body, one that cannot escape being laden with an excess of meaning. In his classic study of stigma, Erving Goffman described how the stigmatized person must constantly manage his or her identity to avoid causing discomfort to others.²⁰ The performers in 999 Eyes are all too familiar with the burden of other people's pity, condescension, and disgust. They see the freak show as an opportunity to showcase their talents rather than their limitations, rescripting the identities available for people with disabilities.

Much as *The Last American Freak Show* emphasizes The 999 Eyes' confrontational and explicit presentation of disability, it also makes considerable effort to show that freaks are just like everyone else. In this, it recalls Tod Browning's 1932 film *Freaks*, which featured some of the best-known congenitally

disabled circus performers of its time. Many of the scenes in the first half of *Freaks* show the disabled actors engaged in ordinary activities like doing housework, socializing, rolling a cigarette, or getting dressed. These scenes aimed to normalize the characters by demonstrating that in spite of their unusual bodies, they are much like everybody else. The problem with *Freaks* was that as the story developed it turned into a horror film, trafficking in more clichéd associations between disability and malfeasance. Like Browning, Butchins expends a certain amount of footage to show his disabled characters engaged in everyday life tasks that normalize their disabilities. All the while, they talk about their feelings, showing their very human capacities for loneliness, pain, friendship, and humor. We see them lounging on a motel bed watching CNN, quarreling over who has to clean up, shopping at the mall, and nursing hangovers. Butchins interviews HEA Lobster Girl in a kitchen where she is cleaning up and preparing a drink. We watch Ken washing dishes and getting lost on the highway. Dierdre takes out the garbage, dressed in jeans and a t-shirt. At the same time, the film constantly reminds us of the



► Fig. 17.12 (AC-129) Dierdre the Dancing Dwarf, Still from *Last American Freak Show*, 2008

freaks' differences from ordinary people, pointing out the ways they are denied opportunities for full social integration.

While nobody is getting rich, the members of The 999 Eyes have chosen bohemian scarcity as an alternative to the poverty and social marginality endured by many people with deforming disabilities.²¹ When asked if she is worried about being exploited, Jackie, who is a musician and songwriter, claims that all forms of entertainment involve some degree of exploitation. "I love performing," she remarks decisively, explaining that because of her disability, "there is no other arena for me to do what I want to do." Deirdre is more ambivalent about her persona, the Dancing Dwarf. Her act includes dancing, walking on glass, eating light bulbs, and making jokes about her short stature (*fig. 17.14*). Onstage, she pushes the audience to confront their preconceptions about little people, while offstage she expresses concern that she is simply playing into stereotypes. "I'm sure if I were in touch with the dwarf community they would hate me for sending off such a bad image," she confesses. Many of the acts play



◀ Fig. 17.13 (AC-128) Cast members from *The Last American Freak Show*, top: Erik the Giant, H E A Lobster Girl, Jason the Lobster Boy, Ken the Elephant Man; bottom: Dierdre the Dancing Dwarf, Jackie the Half Girl. Film Still from *Last American Freak Show*, 2008

with stereotypes. Ken describes being teased as a child and bares his tumor-covered body, demanding that the spectators acknowledge their disgust, but also their desire to look. Jackie sings about being half a woman. Erik the giant claims that during tangles with the law he has avoided arrest because of his great height.

That the freaks willingly flirt with self-exploitation is evident in an episode where they perform as extras in a self-financed horror film by Andrew Getty, grandson of billionaire John Paul Getty. The troupe takes a break from the tour to work with Getty, who explains that he has hired them to add an aura of menacing strangeness to the *mis-en-scène*. "I'm trying to show this town full of strangers," he tells them. "I was thinking the only way to do that is to make them physically abnormal. . . . That's the only way an audience will get it." Butchins, who frequently uses voiceover to reflect on the meaning of the events he's filmed, has little to say during this scene. Perhaps he believed that it would be more powerful if Getty's ridiculous comments simply spoke for themselves. The film rarely ventures beyond the intimate circle formed by the troupe and their closest friends. Getty provides a view from the outside, confirming that disability still functions as an easy signifier of trouble and social disorder. The freaks themselves, accustomed to using their unusual bodies for profit and attention, seem unfazed by Getty's uncritical reliance on such tired clichés. As long as they are paid, they seem to have no problem acting the part of sinister strangers. But even without comment, it's hard to believe they don't enjoy profiting from Getty's foolishness. As in *The 999 Eyes* performances, these self-styled freaks are unconcerned with the promoting the respectable, uplifting images of people with disabilities favored by the able-bodied. They are quite willing to entertain stereotypes as long as they feel



that they have something to gain from the situation.

In deciding to film this troupe, Butchins was aware that he would need to confront his own assumptions about how people with disabilities can best negotiate the cultural meanings of stigma. He represents *The Last Freak Show* as a journey from skepticism to insight. His initial impressions of the troupe are not entirely positive. Their performances seem chaotic and amateurish, and he worries that the show is little more than self-exploitation. As time goes on, he comes to appreciate what the troupe is accomplishing, finding a inspiring sense of purpose beneath their raucous and lighthearted performances that resonates with his own understanding as a person with a disability. At every turn, *The 999 Eyes* reject polite, socially acceptable approaches to their differences. Butchins comes to understand their show as a refusal of able-bodied ideas about how the disabled should behave. Against critics who charge that *The 999 Eyes*, and his film, present negative stereotypes of disability, he affirms their commitment to self-expression, however crude and confrontational. "Go figure," he writes sarcastically on his blog.

A bunch of freaks decide to celebrate diversity in a way of their own choosing, why that will never do. It would seem that they are only allowed to act in ways deemed appropriate by the able bodied, they after all know whats best. . . . Well, not surprisingly, I and the members of the freak show would seek to disagree. It's largely the only time that some members of the troupe get any kind of positive reaction from people. . . . It's not the disability that stops them functioning successfully in society but the barriers and prejudices that society places in front of them that causes the problems. Don't blame the freaks for being freaks, look at yourselves and realise we are all freaks. Perhaps this freak show and my film about them, will give people an opportunity to examine their attitudes to the disabled. That would be good. So, why don't you go and spend a week in a wheelchair, see how it feels.²²

Butchins's anger is palpable as he decries efforts by the able-bodied to set the terms for how people with disabilities should comport themselves. He presents disability less as a problem of bodily

▲ Fig. 17.14 (AC-125) Dierdre the Dancing Dwarf. Still from *Last American Freak Show*, 2008

impairment than a social problem, having to do with an unaccommodating and prejudicial environment. On the one hand, in saying “we are all freaks,” he asks his audience to think about the extent to which normalcy depends on context. But on the other, his suggestion that they “spend a week in a wheelchair” suggests the difficulties of grasping the realities of life with a disability. This is a reminder that people with disabilities are not the same as freaks, that “freak” is not an unshakeable essence but an identity adopted for the purpose of performance. The 999 Eyes invite spectators to explore their own freakishness without allowing them to forget that people with disabilities face exceptional challenges.

As he gains understanding about the troupe, Butchins also acquires insight about his own disability. “Making this film put me in touch with my disability in a way I hadn’t been before,” he said in one film review. “I felt looked-at, whereas I’d always taken great pains to hide my disability.”²³ Butchins claims that seeing how this unusual group of people treat their disabilities made him more comfortable about identifying himself as disabled. And in confronting the resistance of the cinematic establishment to screening his film, he became more outspoken about the right of people with disabilities to represent themselves, even when those representations conflict with able-bodied assumptions about how disability should be seen.

Although he concludes his film on a positive note, Butchins does not shy away from depicting the suffering endured by the disabled members of The 999 Eyes. Some of their discomfort comes from the predictable challenges of life on the road. They often travel in uncomfortable, squalid conditions. The bus is dirty and decrepit. After it breaks down, they exchange it for an RV that is even dirtier. They spend the nights camping in tents, sleeping on borrowed

floors or in cheap motel rooms. They take drugs, drink too much, and don’t get enough sleep. But Butchins also emphasizes that the disabled performers’ experiences differ from those of their able-bodied compatriots. Most of them confess to having been taunted as children. Erik says that, as a child, people “thought I was retarded” because his height made him look twice his age. HEA Lobster Girl admits that she was ashamed of her disability, particularly during high school. In one scene, Jason speaks candidly with Butchins. His surroundings are depressing, a room with paint peeling from the walls, dirt in the corners, cluttered with cheap bric-a-brac. He explains that before joining the freak show, he had avoided people with disabilities. He would try to hide by putting his hands in his pockets. Then he bursts into tears. When Butchins asks Jason why he is crying, he responds: “I just really love my life. And I love my dog, pathetic as that sounds. When you’re alone, she’s been my best friend.” Watching this scene, one can’t help but feel that these are not just tears of happiness. Becoming a part of this troupe has clearly caused Jason to think more deeply about the consequences of his disability and, perhaps, about the inadequacy of the social support he has waiting for him at home.

The most disturbing figure is Ken, who is the oldest member of the troupe and the one whose disability most evidently causes persistent suffering. One of his legs has been amputated, he has a speech impediment, and tumors cover his body. Billing himself as Peg Leg or The Elephant Man, Ken exposes himself from the waist up, while explaining what it is like to live in a body that evokes fear and loathing in other people (*fig. 17.15*). When he removes his prosthesis, the camera repeatedly zooms in on a stump that is reddened, scarred, and covered in tumors. If his performance is designed to give people

► Fig. 17.15 (AC-127) Ken the Elephant Man. Still from *Last American Freak Show*, 2008

a chance to stare at his body in a way that would otherwise be impolite, the camera takes this voyeurism one step further, allowing the film viewer an even more intimate and unsparing look at his disability. At one point, Ken’s stump becomes inflamed, a recurring problem Laurent attributes to a crude amputation that left it vulnerable to infection. In another scene, the camera follows Ken into a mall where shoppers and clerks stare at him in open disgust, one man visibly flinching and turning away. As the tour nears its end, the film focuses on the bickering and dissention that breaks out among the performers. One night, Butchins finds Ken limping alone through darkened streets looking for the performance venue, after having been left behind by the rest of the group. In the next scene, he argues with Sam, who has borrowed his cell phone. She shouts that she is fed up, and throws it at him. Afterward, Ken tells Butchins that he often considers leaving the group, but he seems to have nowhere else to go. By devoting a significant amount of screen time to Ken, the film thus complicates its more affirmative message about the empowering self-expression enabled by the freak show. For Ken in particular, that

opportunity comes at a cost, forcing him to endure the animosity of fellow performers and to further expose his body to the stares of other people.

The Last American Freak Show ends six months after the troupe arrives in Austin, Texas. When Butchins returns to the U.S., he discovers that strained friendships and hurt feelings seem to have been mended. The group is preparing for a new round of performances. Many of them live together in a big house, presided over by one of their two managers, the strong and temperamental Samantha X. As he reflects back on his experience, Butchins claims that his initial doubts about The 999 Eyes have given way to appreciation. “These performers are trying to bring an awareness of their ‘normality’ to peoples [*sic*] attention through entertainment (it is, after all a ‘show’), and that’s a valid and worthwhile, if sometimes, challenging thing to watch,” he writes on his blog. “They deserve support not denigration for what they are doing. This film documents this and as a result is funny, entertaining and sometimes difficult, it makes you feel uncomfortable on occasion and encourages you to examine your preconceptions about disability and that’s the point.”



Butchins argues that the freaks' achievement is admirable, even if—or perhaps because—it sometimes makes us squirm. The fact that the viewer feels uncomfortable should not be a reason to reject the film, but rather to further probe her own attitudes toward disability.

The Last American Freak Show raises timely questions about disability, popular culture, and history in contemporary America. Most of these performers came of age after the ADA, which guaranteed the civil rights of people with disabilities. The decades since its passage have seen significant advancement toward accommodation in schools, the workplace, public space and transportation.²⁴ However, the freaks' stories point to a lingering social intolerance. As children, all of them endured the cruelty of their peers. All continue to face prejudice and lack of access to the full opportunities for work and pleasure enjoyed by their non-disabled counterparts. They perform in a freak show because they believe there is no other venue to showcase their talents. They are fully aware that freak shows of the past often exploited people with disabilities. But they have appropriated the form for the present, turning it into a medium for edgy, alternative self-expression. Performing as freaks gives them an opportunity to talk about their experiences and to show off what they can do, emphasizing ability and accomplishment rather than limitation. In these shows the freaks confront, and then explicitly reject, able-bodied assumptions about how people with



disabilities should behave, with the goal of forcing spectators to interrogate their own preconceptions (fig. 17.16). They do so while surrounded by a tolerant and accepting community. The tour and the group home enable the same kind of continuity between life and work that has always been an aspect of circus culture. It is not simply about doing your act and going home, but a kind of total environment in which life and art are mutually reinforcing.

To put all of this on film is to give it a somewhat different meaning. To approve of what the freaks are doing onstage is not necessarily to like watching them in *The Last American Freak Show*. Unlike a freak show, film enables the viewer to appease her desire to stare without concern that her gaze will be returned. There is an element of voyeurism about *The Last American Freak Show*. Its intimate documentary style allows viewers to look without consequences and in some cases—like the revelation of Ken's stump or Jason's tears—to show things that the performers, no matter how confessional, would never reveal onstage. The story is constructed to create a parallel between Butchins's growing appreciation of the freaks' project, and deepening insight about his own disability. He repeats this message several times over the course of the narrative, without ever speaking openly about the nature of his disability or showing it on film. It is true that within his own logic, there should be a place for privacy as well as disclosure of one's disabilities. But it allows for an uncomfortable dynamic in which the filmmaker remains invisible as a disabled person while his subjects are exposed.

In prompting reflection on the disparity between film and live performance, *The Last American Freak Show* further underscores the significance of The 999 Eyes' project. Part of what makes freak shows work is the fact that they are live, relying on a direct confrontation between spectator and per-

◀ Fig. 17.16 (AC-126) HEA the Lobster Girl. Still from *Last American Freak Show*, 2008



former. The thrill of the freak show is in its promise of a close and unmediated encounter with otherness. Live performance also gives the freak the possibility of agency. However much she is objectified, the freak maintains her capacity to look back, challenging the audience to recognize her humanity and to be mindful of the impulse behind the urge to stare. These conditions cannot be replicated in electronically reproduced forms of media. It is easy to congratulate ourselves on the fact that we no longer tolerate the exploitation of people and animals that once was a routine aspect of circuses past. However, many of the spectacles that were once found at the circus can now be seen on television and the internet, where we can watch them over and over again, from multiple angles and in close-up, with no obligation to acknowledge the fact that we are staring. Without leaving home, we can see a person too fat to get out of bed, a family of little people, a plastic surgery gone horribly wrong, unchecked by anxiety that our gaze may be returned. Like other alternative circuses,

The 999 Eyes restores the sideshow tradition of live performance and the elements of reciprocity, spontaneity, and unpredictability it entailed. However, it is unique in putting disability at the center of its performances. In challenging the audience to confront their own prejudices, it turns the encounter between freak and normal into something quite different than it was for earlier generations. This is a freak show that asks spectators to think about why they are looking. Here they are invited to confront the contradictions between a culture that claims to accept and include people with disabilities, while it continues to treat the disabled body as pathological, loathsome, and sensational. Living with bodies that cannot escape notice, the participants in The 999 Eyes expose themselves, attempting to seize control over how they will be viewed by others. When we flinch at what they're doing, we must ask ourselves whether our dismay might be better directed at a society where integration of people with disabilities is still far more an ideal than a reality (fig. 17.17).

▲ Fig. 17.17 (AC-124) Still from *Last American Freak Show*, 2008

1 While Butchins downplays this aspect of the performers’ lives in the film, see Jack Ruby Murray, “999 Eyes,” for an account of the challenges of traveling with a troupe of people with disabilities, in *Bizarre Life*, Aug. 2009, <http://www.bizarremag.com/weird-news/bizarre-life/7972/999-eyes.html> (accessed July 14, 2010).

2 James Macintyre, “Bafta faces backlash over withdrawal of disability film,” *The Independent* Feb. 8, 2008. <http://www.independent.co.uk/news/media/bafta-faces-backlash-over-withdrawal-of-disability-film-779884.html> (accessed July 20, 2010).

3 John Culhane, *The American Circus: An Illustrated History* (New York: Holt, 1990).

4 Benjamin Reiss, *The Showman and the Slave: Race, Death, and Memory in Barnum’s America* (Cambridge: Harvard University Press, 2001).

5 Bluford Adams, *E. Pluribus Barnum: The Great Showman and the Making of U.S. Popular Culture* (Minneapolis: University of Minnesota Press, 1997); P. T. Barnum, *Struggles and Triumphs, or Forty Years’ Recollections of P. T. Barnum Written by Himself* (New York: Penguin, 1981); A. H. Saxon, *P. T. Barnum: The Legend and the Man* (New York: Columbia University Press, 1989).

6 Quoted in Rachel Adams, *Sideshow U.S.A.: Freaks and the American Cultural Imagination* (Chicago: University of Chicago Press, 2001) 11.

7 Robert Bogdan, *Freak Show: Presenting Human Oddities for Amusement and Profit* (Chicago: University of Chicago P Press 1988) 200–203.

8 Ibid., 166–73.

9 Ashley Montagu, *Elephant Man: A Study in Human Dignity* (New York: Outerbridge and Dienstfrey, 1971); Peter W. Graham and Fritz H. Oehlschlager, *Articulating the Elephant Man: Joseph Merrick and His Interpreters* (Baltimore: Johns Hopkins University Press, 1992).

10 Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Literature and Culture* (New York: Columbia University Press, 1997) 70–77.

11 Sue Schweik, *The Ugly Laws: Disability in Public* (New York: NYU Press, 2009).

12 In Adams, *Sideshow U.S.A.*, 14.

13 *Alive on the Inside* features interviews with Jeanie and Percilla, both widowed, who talk at length about married life.

14 See the film *Gibtown*, directed by Melissa Shachat and Roger Schulte (Decoy Film Properties, Inc., 2001) and Hanspeter Schneider, *The Last Sideshow* (London: Dazed Books, 2004).

15 See for example <http://www.circuses.com/> (accessed July 15, 2010).

16 Adams, *Sideshow U.S.A.*, 210–28.

17 J. Dee Hill, *Freaks and Fire: The Underground Reinvention of Circus* (New York: Soft Skull Press, 2009).

18 See <http://www.999eyes.com/> (accessed July 22, 2010).

19 Joseph Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Three Rivers Press, 1994).

20 Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (New York: Touchstone, 1986) 91–102.

21 When they aren’t on the road, some of the performers have more conventional employment: Dierdre works as a research scientist investigating brain damage in veterans of the Iraq war and Jason has to leave the tour to return to an unspecified job.

22 See <http://angelsstandcorrected.com/>, Jan. 29, 2008 (accessed July 31, 2010).

23 Ryan Gilbey, “How the ‘Freaks’ Got Their Freak On,” *Guardian*, March 27, 2009. <http://www.guardian.co.uk/film/2009/mar/27/last-american-freak-show-disability> (accessed July 31, 2010).

24 Shapiro, *No Pity*.