

Exploring a certain need to be seen versus a desire to be invisible...

Horror Stories: Real and Imagined:

Considering all the talk heard recently about the superb quality of some TV series, '*American Horror Story*' is a disappointment. I still have no interest in finding out whether the ravings about '*The Wire*' or '*Game of Thrones*' are justified—but given a certain morbid fascination—I thought the '*Freak Show*' season would be straight up my alley...

Over the last week, I watched the first three episodes. It started off promisingly: set in Jupiter, Florida in 1952, a German lady [played by Jessica Lange] who owns a freak show in a seedy carnival, visits female Siamese twins (the term used in the era depicted) at the local hospital. Having been taken from their home where their mother was found murdered—they are being treated for possibly self-inflicted injuries. The German impresario persuades the twins to join her troupe...

From that opening, the plot(s) grows twistier than Twisty the homicidal clown, who is also featured in the first episode. It is hard to guess how the strands of narrative of '*Freak Show*' can be stretched into ten more episodes...

Not surprisingly, the troupe of freaks thus far appearing are modelled on the characters of Tod Browning pre-code classic, '*Freaks*'. Unlike the cast of the 1932 original which featured authentic sideshow performers—several of the characters in '*Freak Show*'—the Siamese twins, the bearded lady, the pinheads and the 'lobster boy'—are played by 'normal' actors. Makeup and digital enhancement substitutes for what the prologue note in the original '*Freaks*' film called "the accident of birth."

However, a few real people with unusual bodies are cast: the Guinness Book of Records holder of the smallest woman in the world [Jyoti Amge] plays 'Ma Petite' and 'Legless Suzie', who walks on her hands, is played by a person [Rose Siggins] who really has no legs. Most notably, 'Paul, the Illustrated Seal Boy' with foreshortened arms, is played by Mat Fraser. I instantly recognized him from YouTube clips seen several months ago.



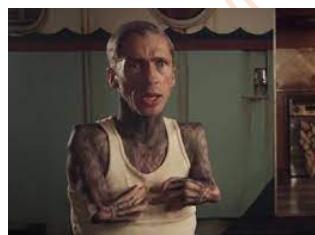
It was a *Ted Talk* titled ‘*I’m not your inspiration, thank you very much!*’ (2014) which indirectly led me to Mat Fraser’s YouTube clips.

The talk was given by an Australian disability activist, Stella Young, apparently just a few months before her untimely death at the age of only thirty-two... In her talk, Young made the case that if the disabilities of people are given attention at all, such attention should be to the practical issues relating to getting on with their lives as ordinary human beings—e.g. better public access for people who depend on wheelchairs.

At the same time, as a person who always got around in a wheelchair, she spoke of her resentment with being “objectified” as an inspirational figure for relatively ordinary achievements. She called the exaggerated depiction of disabled people as heroes: “inspiration porn.”

That was an expression to be remembered. In Googling it, I came upon the name of Mat Fraser, an Englishman who has numerous credits in writing and in acting, both on stage and on screen. In an interview, he flatly declares: “I won’t do inspiration porn!”

Like Stella Young did, he performs stand-up comedy. He has also been a drummer in a punk band. In one of his stage productions, ‘*Sealboy Freak*’ he draws on the life of a sideshow performer from the 1940s who worked under the stage name, ‘Sealo’. Unlike Sealo, Mat Fraser’s short arms are the result of thalidomide.



Among Mat Fraser’s credits is his appearance in a documentary about thalidomide called ‘*Nobody’s Perfect*’ (2008). I found it available for streaming in its entirety on Vimeo.

The documentary was conceived and directed by Nico Von Glasow—a German filmmaker who trained with the legendary Fassbinder. Von Glasow’s documentary brings together twelve thalidomide survivors for interviews and a photoshoot in Cologne. Included in the project are a physicist, a radio broadcaster, a painter, a solicitor, a gardener and a homemaker. Among the twelve are Mat Fraser and the director himself—who also has phocomelic arms.

All the participants have limb deformities of varying severity. Apart from their considerable successes, they speak of their challenges of limb function, the inadequacy of financial supports as well as the anxiety of declining health in aging with the effects of thalidomide. Still, the general impression is of a group of successful and relatively content early middle-aged adults.

The topics of the interviews conducted by Von Glasow range from banter about penis size (with the men) to pointed questions such as: “Which part of your body do you most dislike?” And “Did your mother ever tell you how she felt on the day you were born?”

With the exception of the photogenic Mat Fraser— all twelve admit to a distracting self-consciousness about being stared at...

“It gets draining,” says one of the women.

In the discussions, Von Glasow, does not hide his own vulnerabilities. In one turn of dark German irony, he says that his mother would have been justified had she decided to terminate her pregnancy before his birth...

Meanwhile, he leads up to the photoshoot. Each participant is to be the subject of an artistic or whimsical photo. Props are included. Multi-coloured scarves will float down on the artist, the equestrian will appear behind a horse and the gardener beside a tree. Mat Fraser will be holding a Shakespearean comedy mask against his groin. Yet apart from the accoutrements— each participant will be photographed naked...

“It is a way of conquering our ultimate fear,” Von Glasow says.

The film director is no less nervous than the others about taking off his clothes. He chooses to have his photo taken with his 10-year-old daughter. Fully clothed, she will laughingly point towards her funny old dad...

All the participants go through with the ‘ordeal’.

Then comes the *piece de resistance* of the project: The photos are blown up and displayed in front of the Cologne art gallery. The reaction to the display by passersby is mixed: there is curiosity, amusement, admiration, indifference— even disgust (“I think it is tasteless,” one codger grimaces...) A few members of the group are shown watching the reactions from the back of the square.

“I am so used to being stared at,” one of the women smiles. “Now for the first time I feel on the offensive— look at me!”

Indeed, for anyone who feels they would die before showing their naked body publicly— what could be more liberating?



After the public photo display is a scene of the group gathered around a candlelit banquet table. Any parallel with the wedding banquet scene in the 1932 'Freaks' film, might not be coincidental. Indeed, Von Glasow's dark irony is already much in evidence... Mat Fraser who serves the wine, jokingly refers to the tableau as "the last supper"...

By this time, the camera records the 'normal' diversity one would expect in any random group of twelve adults: a mix of the fair and plain-featured, the talkative and the reserved; the serious and the mirthful. The armless woman delicately sipping wine with her feet hardly catches the viewer's attention...



In a climactic scene that follows, Von Glasow tries to deliver his blown-up photo directly to the office of Michael Wirtz, owner of the Gruenthal pharmaceutical corporation. Earlier in the film, Gruenthal has been identified as the company that originally marketed thalidomide. Up to the time of the film's making, the company had resisted all appeals for a formal apology. Any financial support Gruenthal had extended to survivors was minimal... References to the company by the group were spoken in anger, bitterness or resignation.

In all his attempts to see Wirtz or other company directors, Von Glasow is put off by uneasy receptionists. He finally leaves his photo leaning against the outside wall of the headquarters...

The final scene of the film parallels the opening. Von Glasow is shown hand in hand with his daughter. In bathing suits, they are walking from a beach towards the sea. His nonchalance among passersby suggests that the 'Nobody's Perfect' project provided him a little therapy in pursuit of "conquering the ultimate fear."

An uplifting ending? If that was achieved—it was admirably done without inspiration porn...



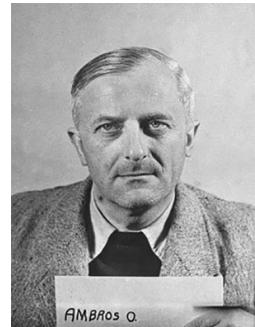


Searching later for background on thalidomide, I came across a Canadian documentary, 'No Limits' (2016).

The film begins with a chilling encapsulation of the history of the drug once marketed as a safe treatment for morning sickness... Black and white footage from the 1940s reveals that Heinrich Mückter, a pharmacologist who developed vaccines tested on prisoners in Nazi concentration camps, went on to work for the Gruenthal corporation. There, as head of research, he steered the patenting of a drug called Contergan. Along with the Wirtz family owners of Gruenthal, he would make a fortune from its sale. From 1957 up until its banning in 1961, that drug would cause severe birth defects in upwards of 10,000 children.



fwf



Another director of Gruenthal, Otto Ambros, developed nerve gas for the Nazis. In the late 1950s, Ambros helped fumble a deal with the German state government which for decades gave Gruenthal immunity from prosecution from thalidomide survivors...

This history is interspersed with montage images of some of the children affected. Deformed babies in stark black and white become smiling toddlers in blurry home movies. Teens anxious about dating become middle-aged men and women reflecting on their lives...

Among the featured "thalidomiders" is a German woman (of grave demeanor) who grew up near the town of Hadamar, in Hesse. The name of her town has become notorious in having once been the site of the Hadamar euthanasia centre. She is shown among a group protesting outside a Gruenthal facility...

She is one of the lucky few whose limb deformity from thalidomide was relatively mild. Her single shortened arm is hardly noticeable. Still, she speaks of being haunted by the realization of

having escaped Hitler's '*Aktion T4*' program ("mercy-killing" of those deemed "unfit for life") only by being born sixteen years after the war...

Prominently featured in the documentary is Alvin L.— born armless from the shoulders and put up for adoption. His adoptive parents were a middle-class Saskatchewan couple whom he credits with nurturing his can-do spirit. Video clips show him in a variety of 'normal' activities: performing in a high school musical, dressing himself, driving and playing piano. Lifting a coffee cup, he charmingly points out that in the absence of fingers— feet quite naturally become hands... Further scenes show him singing in a fund-raising telethon and engaged in his primary work as a motivational speaker. He is shown delivering an upbeat talk to a high school audience after which he plays a rousing drum solo to a standing ovation...

Also among the profiled interviewees is Nico Von Glasow. Among other topics (e.g. his bitterness against Gruenthal), he speaks of the genesis of the '*Nobody's Perfect*' documentary a decade earlier. He says that when the production company which hired him first proposed the project, he felt patronized.

"I said: 'what the hell do I know about thalidomide?'"

He then admits that prior to that time he had an aversion to seeing others whose bodies—like his own— were deformed by thalidomide...

In his retelling of that climactic moment, he chuckles. "My wife said 'Nico— time to look the devil in the eye!'"

Perhaps tellingly, Mat Fraser does not appear in the 2016 documentary. One might speculate that it was filmed at the time when he was busy with other projects such as '*Freak Show.*' Might there have been another reason? Perhaps he felt that certain scenes in '*No Limits*' veered too close to inspiration porn...



Questions (only marginally related to these insightful documentaries) persist: Why do people who obviously hate being stared at— still often seem to have a need for attention? Why do those who would like their unusual bodies to be ‘normalized’— still often regard themselves as ‘special’?

In exploring these questions, one might begin by considering the crudest form of attention ever given to people with unusual bodies: the freak show.

Not so long ago, the only option of semi-independence for certain people with unusual bodies was to exhibit themselves in carnivals. However exploited by managers (and often by their own families) the freak show was a meal ticket—and if the movie depictions are true—a fellowship with other carnival performers...

Yet no human being can be passively content to be a mere object for the creepy titillation of yahoos. Often, ‘freaks’ were determined to show that they could be skilled entertainers. One might take, for example, the cojoined twins who appeared in the 1932 ‘*Freaks*’ film:

The Hilton sisters— Daisy and Violet— apparently performed song and dance routines. One twin reputedly was an adept saxophonist and the other a violinist. Unfortunately, like all labelled ‘freaks’, they could never know how much their performances were appreciated apart from the spectacle of their bodies...



Though carnival sideshows are history—freak-show style entertainment is more popular than ever. Its venues have simply shifted from circus tents to movies, reality TV—and more recently to the internet...

You-Tube is bursting with uploaded clips of ‘freakish’ performances. Clips of legless gymnasts vie with those of legless mountain climbers. If one tires of one-armed guitar playing—there are clips of armless guitarists playing with their toes. Viewers can be inspired by the courage of disabled people performing feats one might have thought impossible—or they can unashamedly ogle... In pursuit of either desire, such clips can be consumed like pinches of cocaine...

Yet in seeming contradiction, a disabled person’s skilled performance which is entirely unaffected by his/her particular disability are seen as equally ‘inspiring’. One might think of the renowned German baritone, Thomas Quasthoff, who also happens to be a thalidomide survivor. His foreshortened arms are no physical hindrance whatsoever upon the exquisitely tuned instrument that is his voice... Still, he has been the subject of numerous inspiration profiles—including one on the American TV newsmagazine, ‘60 Minutes’...

So, it seems that even a virtuoso can never be sure that his art is fully appreciated outside the context of his bodily appearance... The disabled or unusually-bodied performer is thereby often even more driven to prove himself/herself...

On the other hand, it is entirely possible for a disabled performer to believe that his/her talent is larger than it really is... This tendency is especially notable in those who have borne their unusual bodies from infancy or from birth. As they grow and naturally adapt to their disabilities, they tend to be subject to over-praise. That attention often confers in them a sense of their not just being different—but being endowed with ‘special’ talents... Thus, they are often given to obsessively challenging themselves in athletic prowess or artistic endeavour.

In ‘normal’ venues, the disabled performer is sure to be lauded as inspirational. No matter how many sour notes he may hit, an armless trumpet player will receive a standing ovation...

In more recent years, the disabled performer or artist has had the option in performing in special festivals dedicated to showcasing the artistry of the disabled. Festivals such as ‘Kickstart’ in Canada have aimed to celebrate the talents of the participants while ‘normalizing’ disability for non-disabled audiences. While lauding the good intentions, a question might still be asked: do uniquely talented artists who happen to have disabilities really need a special venue analogous to the Special Olympics for disabled athletes? Of course, some of the performances at such festivals might be outstanding—but whether virtuoso or mediocre—all are guaranteed the same patronizing praise...



There has certainly been progress in the ‘normalization’ of bodies once hidden to avoid ‘upsetting’ the public. Just as with the growing appearance of ‘visible minorities’ in media a generation ago, the increasing appearance of a range of disabled people on screens is slowly educating the public in the plain facts of human diversity. Wheelchairs no longer seem attached to the personalities of the people who sit in them. TV viewers are learning not to stare at the deformed hands of a weathergirl who happens to have ectrodactyly...

Yet in everyday life, unusually bodied and disabled people often continue to struggle in a double bind. As much as they resent patronization—too often they continue to fuel it by compulsive and unnecessary ‘performances’... The felt pressure to perform is rather more subtle today than it was in the era of the Hilton Sisters. Performance, in a broader sense—is not only song and dance or feats of athletic prowess. In everyday occurrence, it is just as likely to involve demonstrations of wit, courage or pluckiness. Yet at the core is the same felt pressure: a need to prove one’s fully fledged humanity...

It will be a better world when people with abnormal bodies no longer feel ‘special’. An ability to be ‘ordinary’—and occasionally invisible—could be quite as liberating for them as the display of their nude photos in a public square...



...so, should I watch the remaining 10 episodes of ‘*Freak Show*’?

I am already convinced that missing several award-winning TV series of the last several years has been no loss. I will happily continue to hue to a two-hour limit movie format for TV entertainment. Plots stretched over seasonal episodes move far too slowly for my patience...

As for ‘*Freak Show*’: The surfeit of gore and soft-core titillation has been a poor substitute for a lack of suspense. So far, I have noted mostly plagiarized tropes of classics in the horror genre...

By my reckoning, Tod Browning’s 1932 ‘*Freaks*’ remains that most frightening horror movie of all time. Never has a nightmare been better captured than in its climactic scene. The ‘human caterpillar’ (played by a real limbless sideshow performer) with knife in mouth who crawls under the circus wagons toward the screaming Cleopatra to exact just revenge—is also crawling relentlessly towards the viewer...

If I do continue watching *American Horror Story*—a finger will be on the fast forward button. Yet as part of ongoing informal research—I will carefully note further depictions of ‘freaks’...

2017, November



fwt