

## THE OPEN DOOR: FIVE FOUNDATIONAL FILMS THAT SEEDED THE REPRESENTATION OF HUMAN RIGHTS FOR PERSONS WITH DISABILITIES

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*A door opens and a few people stumble into the light and an empty space. They seemed disoriented, unsure of where they are, and a few French nuns move them along. In the corner there's a man hunched over on a bench who seems frightened, almost like a wounded animal. Someone unlocks an iron door, and more people enter, dressed in period costumes of the French Revolution. Another man dressed in rags, obviously disabled in some way, drags himself across the room and hands a woman in a formal dress a bouquet of flowers. Someone kneeling on the floor is violently grabbed by two male orderlies in blue hospital robes; his scream muffled by their hands. A trumpet fanfare sounds and a master of ceremonies in a tuxedo and top hat addresses the camera from the other side of prison bars. He proclaims:*

*As director of the clinic of Charenton, I should like to welcome you to this salon. And to one of our residents a note of thanks is due, Monsieur de Sade, who wrote and produced this play for your delectation and for our patient's rehabilitation. We ask your kindly indulgence with a cast never on stage before coming to Charenton. But each inmate, I assure you, will try to pull his weight. We're modern, enlightened, and we don't agree with locking up patients. We prefer therapy through education and especially art so that our hospital can play its part faithfully following the Declaration of Human Rights (cynical laughing in the background). I agree with our author, Monsieur de Sade, that his play set in our modern 'bath house' will not be marred by all these instruments of mental and physical hygiene. Quite the contrary, they set the scene for Monsieur de Sade's play where he has tried to show how Jean Paul Marat died and how he waited in his bath before Charlotte Corday came knocking at his door*

(MARAT/SADE, 2001).

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Thus begins Peter Brook's famous 1967 adaptation of the play *The Persecution and Assassination of Jean-Paul Marat as Performed by the Inmates of the Asylum of Charenton under the Direction of the Marquis de Sade*, otherwise known as *Marat/Sade* (2001). Set in the Charenton Asylum, just after the French Revolution, the play was directed by the Marquis de Sade with actors who were inmates of the asylum. Essentially a play-within-a-play, the story takes place in 1808, when historically, de Sade was imprisoned there and did direct performances with inmates. But his play concerns the famous writer Marat who was murdered in his bath by Charlotte Corday during the Revolution in 1793. The director of hospital Monsieur Coulmier, (who welcomed everyone), and who supervises the performance is a supporter of Napoleon's post-revolutionary government and he hopes the play will support his patriotic views.

During the performance, however, the patients had other things in mind and often break away from the text to express themselves. They felt no better after the revolution and their claims about rights and justice are repressed as the nurses and orderlies step in from time to time to keep order. Meanwhile de Sade sits idly by, debating philosophy with Marat and reflecting on the proceedings with detached amusement. Consumed with his own self-serving erotic and nihilistic beliefs, he even orders his own whipping by Charlotte Corday.

Peter Brook staged the play with the Royal Shakespeare Company under Antonin Artaud's axiom that "The theatre must give us everything that is in crime, war or madness, if it is to recover its necessity."<sup>1</sup> Brook translated Artaud's theories into practice by foregrounding the Charenton inmates with disabilities. In the history of avant-garde theatre (and indeed documentary film) *Marat/Sade* was a landmark performance, breaking away from established theatre conventions and bringing dramatic performance back to a mystical, primal state. By stressing scenes of violence, sadism, and insanity, the performance threatened the fragile boundary between the audience and the performers and made a mockery of psychotherapy that the play-within-the-play was supposed to achieve.

Peter Brook is famous for his notion of the stage as an "empty space" that allows actors to create a physical world from scratch.<sup>2</sup> For Brook, the empty space of the theatre makes it possible for a new phenomenon to come to life. With *Marat/Sade*, a door was opened onto a world of disability, among other political issues. That the play/film is introduced as a "human rights" response to psychosocial disabilities with drama therapy, the production allowed for a critical inversion to surface. Not only can the performance be read as a critique of classical first-generation civic and political rights in the time of the French Revolution (yet alone the late 1960s when the production was staged), but also second-generation economic and social rights that affects health and rehabilitative services for those with disabilities.

Brook states that one goes to the theatre to find life, and that there should be no difference between the two. But theatre, and for all intensive purposes a film as well, should make life more visible, more concentrated, more readable, and more intense. That irresistible presence of life—what Brook talks about in his writings—is the spark that lights up and intensifies the empty space where we witness life unfolding in front of us. In *Marat/Sade*, Brook crafted a landmark way of filming theatre,

which would influence all subsequent performative documentaries. One could argue that *Marat/Sade* was a stand-alone film as much as it was a documentation of a theatre piece. His use of close-ups and cutaways, handheld cameras tracking the actors, silhouettes and out-of-focus techniques, combined the creative strategies of art cinema with avant-garde theatre.

But it's the degree of reflexivity in Brook's production that's so compelling. If theatre is to be a total experience, it must also involve the audience in the construction of the empty space. As *Marat/Sade* is a play-within-a-play, there are audience members among the actors themselves; the director of Charenton invites his wife and daughter into the bath house and he delivers his introduction to the French aristocrats who are seated just on the other side of the iron bars of the prison. This too was a historical fact, that the wealthy upper class would watch the therapeutic performances by the inmates at Charenton. The camera from time to time pulls back and we see the exchange between the actors and the audience. The audience is silhouetted in front of the bathhouse and the effect places us as film viewers right behind those seated on the other side of the bars, as if we too were complicit. And when the inmates are on the verge of total anarchy, which they are several times during the play, the director of the hospital stops the action, chastises de Sade, and threatens to halt the production so as not to offend the audience.

From the reviews of when Brook staged *Marat/Sade* in London and New York in the mid-1960s, we know that audiences were offended, many walked out, and others became physically ill watching the play.<sup>3</sup> It wasn't just the drooling, nose-running, foaming at the mouth, muttering, moaning, twitching, shaking, weeping, screaming, and all the physical symptoms associated with madness. It was more the brutal repression that the orderlies enacted on the inmates to snuff out free expression. Inmates were beaten down, chained to the wall, and dragged across the stage in the name of censorship. This was shock theatre to its core. And what it mirrored (besides a larger social madness in the late 1960s) was the contemporary asylum and its supposed rehabilitative treatment of the mentally disabled.

In his book, *Theatre and Its Double*, Artaud extols that performance must physically affect the audience, that the total experience of the theatre is as much about your body as it is your senses.<sup>4</sup> Life on the stage must pierce you; wound you in some way for it to be effective. He also argued that theatre is essential because it does away with any media interface – one comes up against other bodies and souls face to face. A documentary film can also be a powerful experience given the right cinematic strategies. The multiple reflexive strategies of *Marat/Sade* forces even viewers of the film to acknowledge their role in the exchange process, especially at the close of the performance when a riot breaks out and the prisoners exact brutal revenge (class warfare) on the hospital staff and the director's family caught onstage. The piece ends with the prisoners climbing the bars barely separating them from those patrons of the arts, which by extension, includes us as viewers. The revolution on the stage was about rights, which the inmates kept asking for the whole performance. But there was no resolution in the play, nothing except a final exhortation to Take a Stand! That was an apt slogan for the times but it also left all conclusions and interpretation up to the audience.



At the time in the 1960s, the international human rights movement was entering what some scholars call the third generation of human rights focusing on experiential or collective rights.<sup>5</sup> Instead of the ontological focus on individual freedoms, the movement was beginning to recognize various collective struggles. In the name of self-determination, countries were fighting for independence from colonial powers. The civil rights movement was raging in the U.S. The peace movement was a growing international force. The women's movement gained momentum. The children's rights movement would eventually fall into place. Indigenous rights were spreading through traditional homelands. And eventually collectives would begin such as the gay, lesbian, bisexual, and transgendered (LGBT) movements.

The disability rights movement also began to take shape. The history of disability rights is checkered in the sense that local, national struggles tended to precede any wider international movement. In the United States where I'm writing from, the history of disability rights actually began just after WWI when soldiers returned home with tragic injuries that led to lifelong problems.<sup>6</sup> In the 1920s, vocational rehabilitation acts were passed to provide services to veterans. But the recognition that wounded soldiers needed special care was still a very exclusive understanding of disabilities. Until the 1960s, anyone with a disability was deemed to be "handicapped," and the prevailing wisdom was to institutionalize patients and keep anyone with a disability out of public view.

Activism took off in the 1970s when people with disabilities lobbied Congress, staged sit-ins at various cities, and organized marches for rights. Borrowing from other collective struggles, the movement advocated for civil rights language and laws to protect all kinds of disabilities. This pluralistic approach, setting aside specific goals of niche groups affiliated with different kinds of disabilities, was what gave this activism its strength and collective ethos.

The major laws that were passed included the 1973 Rehabilitation Act, the 1975 Education for All Handicapped Children Act, and the 1990 Americans with Disabilities Act.<sup>7</sup> What these Acts guaranteed was that anyone with a physical, mental, visual, auditory, or any other kind of disability, would have equal opportunities in employment, housing, and education. Children and youth would have appropriate and free public education in the least restrictive environment possible. Access to public areas, especially public transportation, was a crucial turning point. The right to adaptive technologies, enabling people to communicate, express themselves, study and learn, and work also became easier with new legislation. And so-called lifestyle issues, the ability of individuals to live independently became an important focus of disability activism.

One could argue that the goal of the collective movement was inclusion into mainstream society and an end to treating persons with disabilities with exclusionary practices and the 19<sup>th</sup> century asylum approach to treatment such as depicted in *Marat/Sade*. Inclusion also meant creating solidarity with activists who were not affected with disabilities. Filmmakers played an important role here because the movement needed all the help it could get including visual representation. In the 1960s, filmmakers working with disability issues did not necessarily see themselves as human rights workers. They tended to work under the banner of social reform. Today, this same group is screening their documentaries in human rights film festivals

around the world. In fact, it would be hard to even speak about contemporary human rights without visualizing the struggle in concrete terms.

There are many films about disability rights today—both documentary and feature—and people have gone to great lengths to catalogue such films under their appropriate disability headings.<sup>8</sup> There's even special disability rights film festivals. But there are also some seminal films that seeded the wider movement and paved the way for the recognition and visual awareness that we have today concerning disability. My intention with this paper is to mark five of these landmark films and to suggest some of the more poetical strategies of representing disability rights. The poetical side to representing disability offers more open-ended interpretations and perhaps, because such films have no closure or overt policy recommendations, these film projects have a much longer life span of holding public interest. The five films discussed here are now considered classics in the documentation of disability.

As a professor of human rights and media, many of my students are studying to become documentary filmmakers and disability rights are one of the many rights-based themes that they work on. To be sure, from a conceptual framework approach towards human rights, specific impairments are never by themselves the only issue. The conceptual framework approach seeks to understand the depth and complexity of each human rights violation and make holistic connections between all rights.<sup>9</sup> For example; women with disabilities are doubly vulnerable because they suffer oppression as women and as persons with disabilities. Children with disabilities also need a more holistic conceptual approach. Disabled victims of armed conflict, persons with disabilities who are forced into migration, or persons who suffer from poverty in addition to any physical, mental, or sensory impairment need a sophisticated human rights approach.



One of the Ur-films in depicting disability is Fredrick Wiseman's 1967 film *Titicut Follies* (1967). This is a much talked about film in the history of documentary practice but seldom seen until recently. Its history is complicated by ethical questions of consent and the public's right to know. The film was shot inside the Bridgewater State Hospital for the "criminally insane," which was administrated by the State of Massachusetts Department of Corrections, and not the Department of Mental Health. Like Charenton, this place was essentially a prison, and among the 2000 men who were there at the time, only 15% were actually convicted of a crime.<sup>10</sup>

How Wiseman and his cameraman, the famed ethnographic filmmaker Robert Gardner, gained access to the facilities and their subjects was a question that would be debated in the courts for years afterwards. Could the hospital superintendent, ostensibly the legal caretaker, grant consent for everyone under his charges? Not five minutes into the film, the men are lined up for strip search, naked and humiliated in front of each other and the guards. Shot in soft 16mm black and white tones, the scene is sobering November window into how those with psychosocial disabilities were warehoused at the time.

The next scene presents, in what might be understood as the "normalization of deviance," an intake interview with an inmate named Mitch and Dr. Ross, one of the two psychiatrists for the entire prison population. That they are later named in the film is astonishing given their conversation. While Mitch openly acknowledges

his pedophilia, the psychiatrist sits there chain-smoking wanting to know how he feels about his sexual deviance and why he masturbates three times a day. When Mitch genuinely asks if he'll receive help for his problems at the hospital, Dr. Ross wonders himself and replies: "You'll get it here, I guess." The simplicity of this response and the deduction of their conversation are staggering. There is no therapy here, no meaningful exchange of knowledge, and no treatment plan. There's only the institutional normalization of power and shame while constructing a deviant other.

Other scenes in the film are not so subtle. This is not the Royal Shakespeare Company acting out roles in the asylum; this is the real thing shot in a direct cinema technique of careful observation with no questioning or voiceover or any external sound track than what was happening at any given moment at Bridgewater. One man carrying a newspaper was talking a mile a minute mixing scraps of what he might have just read with a kind of gibberish in a constant stream of incomprehension. He later offers his blessings to the other inmates and, among the many critics of this film, the Catholic Church even condemned this scene.

The men out in the yard seem isolated and lonely. Some men talk only to themselves. One man, shaking and twitching, standing in the middle of the field openly masturbates. Another plays his soulful trombone by himself. Others hold their own soapbox, spouting their political beliefs and have arguments with other inmates on the madness of the Vietnam War. One man though seems different. A man named Vladimir, speaking fluent if measured English with an East European accent, stops Dr. Ross in the yard. He pleads his case that he was misdiagnosed and he should not be in the hospital. He's tone is urgent; he feels he's getting worse the longer he stays. The psychiatrist offers a kind of mocking cynicism, smiling and reminding Vladimir of his diagnosis of being a schizophrenic paranoia. Vladimir then argues, who has the right to define what these labels mean in society.

The most heartbreaking scenes are when the men are led to their cells, naked and isolated in their rooms. The cells themselves are shockingly bare, nothing but a cold floor, brick walls, and a window covered with metal guards. One naked man paces back and forth stamping the floor in his bare feet and pounding on the window and when he finally leans into a corner, you see the bloodstains where he must pound his own face against the wall. Meanwhile the guards openly taunt the men, constantly asking them why their rooms are so dirty. One man in the hall drops to his knees to hide his private parts. Another cups his hands over his groin in embarrassment. It's not clear whether these reactions are related to the presence of a camera. Having watched the film many times, I think these men must cover themselves even without a film crew present because the situation is so humiliating.

At the time, "elderly rights" was not a well-defined human rights concept. But many of the men at Bridgewater were in the twilight of their lives with no one to care for them making their situation even more painful to watch. The worst case is when a man refuses to eat and he's manually strapped to a table. He's also naked. Dr. Ross greases a rubber tube and sticks it into his nose all the way down into his stomach. He then stands on a chair above the patient and pours a kind of soup into a funnel feeding into the tube. He even jokingly asks if anyone has any good whisky for the patient while his cigarette ash is about to fall into the funnel.

When the camera closes in on the man's face, a teardrop runs down his cheek. The scene is cut with the same man's face being shaved and then back to the forced feeding and then back again to his face in a different situation as someone pulls open his eyes with tweezers and sticks cotton balls under his eyelids. Only when his body is wrapped in the hospital morgue and stuck into a cooler does the scene register. And when his body is lowered into the ground, the scene presages one of the burning human rights issues for prisons today, that being "length of incarceration" and the fact that many elderly people now die inside prisons.

Late in the film, Vladimir makes his case in front of a board of medical experts and hospital nurses. One of the doctors says: "Now as I told you before, if I see enough improvement..." "Vladimir lucidly cuts him off: "But how can I improve when day by day I'm getting worse, and now you tell me, until you see an improvement, but each time I get worse. So obviously it's the treatment I'm getting, or the situation, or the place, or the patients, or the inmates. I was supposed to only come down here for observation. What kind of observation did I get?" (TITICUT FOLLIES, 1967).

Vladimir continues, arguing eloquently saying that he's been caught in the system now for a year and a half, that he wants to go back to where he belongs, that at least back in the regular prison there was a school and a gym, and that the medicine is making his mind worse. The board is unmoved and when they ask him to leave they confer among themselves on camera. They note their surprise that he learned to speak English while in prison, and that he also passed his parole before being sent over to the hospital. The chief psychiatrist surmised that Vladimir was falling apart and that his anxiety is a common symptom of the anti-depressants and that what they should now do is administer heavier doses of tranquilizers.

At the end, the film circles back to the opening scene; an annual talent show put on by the prisoners and guards called *Titicut Follies*, hence the name of the film. As the patients and the staff sing *So Long for Now*, the performance reminds us that the public exhibition of inmates in institutional "mad-houses" like Charenton, reaches back hundreds of years. That the follies were presented as amusement in the name of rehabilitation is a travesty considering what Wiseman shows between the opening and closing scenes.

From the beginning the film caused controversy. Before it even opened at the New York Film Festival in 1968, the film was in a legal mess.<sup>11</sup> A social worker, without ever seeing the film, read there was full frontal nudity among the inmates and wrote a letter to the governor of Massachusetts complaining that such a film violates the dignity of its subjects. The state of Massachusetts then tried to get an injunction to stop the opening, saying the film violated the rights to privacy of the inmates and the guards. Wiseman countered saying he received legal written permission from the hospital superintendent and oral consent from the inmates and the staff. Furthermore, at no time during the 29 days of shooting were Wiseman or Gardner asked not to film something. While the legal issues were being sorted out in Massachusetts, a New York state court allowed the film to be shown.

*Titicut Follies* opened at the New York Film Festival (and later commercially in New York) to much acclaim as a bracing expose of a very troubled place. Its somber tones, soft focus at times, and open editing style forever marked *Titicut Follies* as an art film as much as it was an observational piece of investigative journalism.

But unlike expository films, there's no narrative per se in *Titicut Follies*, no policy recommendations, or any sense of closure in the film. Today, when students study the history of documentary films, *Titicut Follies* is a benchmark example of direct cinema technique, or the non-intervention of the filmmaker and an editing style to give the illusion of real time unfolding. I use it in my class *The Poetics of Witnessing* to demonstrate how one can study and represent human rights violations in a poetic manner that allows the film to be open to multiple interpretations.

But back in the courts up in Massachusetts in 1968, a Superior Court judge ordered that the film must be banned from general distribution. Since Wiseman himself lived in Boston and was a resident of Massachusetts, he was legally bound by this decision. But the judge went further and asked that all copies of the film and its negatives be destroyed because the film violated the patient's privacy and dignity (not to mention the negative representation it cast on the State). And while Wiseman, who himself was a lawyer and a former professor of law, argued his case, this was the first time in American history that a film was legally banned for reasons other than obscenity or national security.

From the perspective of the filmmaker, what is more important here, the privacy of the individual inmate or the public's right to know? Considering the context, this is a human rights dilemma involving the ethics of image making and the right of free speech. The First Amendment to the U.S. Constitution enshrines this very right itself. And Wiseman has consistently argued through his dozens of subsequent films after *Titicut Follies* that the public has the right to know what goes on in its tax-funded institutions. In fact, Wiseman has stated that if the First Amendment protects anything, it's a journalist's right to report about what goes on inside prisons. The irony at the state level is that it took a film for the state of Massachusetts to recognize the right to privacy for the first time. In the end, this ethical dilemma was not solved but the question lingered for years. Was the court's decision more of a violation of the civil liberties of the film than an infringement on the rights of the inmates?

More lawsuits and decisions and appeals followed. But outside of special and restrictive screenings for educational purposes, the film was effectively banned for 20 years. Finally, in 1987, families of several inmates who died at Bridgewater sued the hospital and claimed there was direct correlation between not allowing the film to be seen and the deaths of their loved ones. They called for the film to be used as evidence of the brutal mistreatment of inmates while incarcerated at Bridgewater. In other words, if the public had knowledge of the conditions at the hospital, it might have forced the state to change its institutional practices towards inmates with psychosocial disabilities.

Finally, in 1991, the superior courts in Massachusetts allowed the film to be released to the general public. However, the court ordered that the film must include an explanation that the prison for the criminally insane at Bridgewater has been reformed. But as one doctor, Thomas Szasz, has argued in an essay on *Titicut Follies*, the hospital is still surrounded by barbed wire, policed by hundreds of guards, and that no matter that there are now dozens of nurses, psychiatrists, psychologists and social workers, they are all still jailers (SZASZ, 2007). Today, the state hospital at Bridgewater is called a "health care facility." But despite the renaming, Szasz points

out that behind the façade, there's still the treatment of persons with psychosocial disabilities with pseudo-medical diagnoses and questionable therapies. Like *Marat/Sade*, prisoners with psychosocial disabilities are still on the other side of the bars.



As disability rights moved into a more international platform of awareness and even legal redress, activists looked at the normative standards of human rights to guide the movement. These standards are based in the U.N. Charter, the Universal Declaration of Human Rights, and the related covenants and instruments including the recent U.N. Convention on the Human Rights of Persons with Disabilities.<sup>12</sup> There's two ways to read disability rights into the normative standards. First, there's the general language that guarantees fundamental freedoms "without distinction" of any kind. From this perspective, everyone should have equal access to housing, education, social services, health care, and employment. Furthermore, everyone should have the right to participate in all aspects of social, political, economic, and cultural life in society. And everyone has the right to be treated with dignity and respect.

There's also language in more specific covenants and instruments especially those for women, children, and the Convention against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment.<sup>13</sup> In theory, one could cite that the conditions at Bridgewater consisted of serious human rights violations that were cruel and degrading, if not torture. But *Titicut Follies* should not be read as a historical film. There are many similar places today where conditions are just as bad if not worse.

In 2003, the NGO Disability Rights International (DRI) teamed up with the video advocacy NGO Witness (both based out of New York) to document 460 patients at the Neuro-Psychiatric Hospital in Paraguay.<sup>14</sup> Partnering with a third local NGO, video was clandestinely captured during tours of the hospital. The footage is shocking, even worse than what Wiseman and Gardner brought out of Bridgewater. The video was then presented as evidence before the Inter-American Commission on Human Rights in Costa Rica (of which Paraguay is a member).<sup>15</sup> Specifically, the case documented two teenage boys who were locked in isolation for over four years. They were being kept in their cells naked, with no access to toilet facilities, and their floors and walls were covered with feces. The common yard for all of patients was littered with garbage and broken glass and at one point during the video, one of the patients urinates in public and another drinks water out of a puddle like a dog.

There are probably no human rights issues here without visual evidence just as there was no story at Abu Ghraib without the photographic images of Iraqi prisoners abused by American soldiers. DRI and Witness streamed the video on their websites, and worked with media networks to bring the case to a wider level of awareness. Presenting the visual documentation as evidence, the NGOs showed dehumanizing and life-threatening conditions at the hospital, that the most basic sanitary conditions were missing, and that patients were not receiving appropriate medical attention. Moreover, they proved that Paraguay had failed in its human rights obligations to treat and rehabilitate those with psychosocial disabilities. The footage and the case eventually shamed the State into reforming the hospital. Although reforms were made, DRI and Witness issued a follow-up video showing that the patients were still

in critical conditions at the hospital and they called for habilitation and eventual reintegration into the community for the patients.

The standards that DRI called upon are drawn from Principals for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care adopted at the United Nations in 1991. These are not binding international covenants as much as they are principals, ideals to strive for, and moral guidelines. Among the 25 articles, two are named in the film; that the patient has the right to treatment in the least restrictive environment and that treatment should be directed towards enhancing personal autonomy. The degrading treatment that their videos show is similar to *Titicut Follies* in that they document serious human rights violations. This is but one strategy of visual human rights, to shine a light on a troubled spot in the world, and to stimulate a change process.

Today, we have a new set of international standards, more legally binding too. The U.N. Convention on the Human Rights of Persons with Disabilities is an international treaty that is signed and ratified by member states.<sup>16</sup> To date, as of January 2011, 147 states have signed and 97 states are parties to the treaty with the latest being the European Union which collectively ratified the document in December of 2010. What the treaty promotes and protects are the classic issues such dignity and integrity, freedom and autonomy, equality and non-discrimination, accessibility and opportunity, inclusion and full participation, respect for difference and acceptance of diversity. These are the very themes that contemporary filmmakers focus on when representing disability. But these ideas are nothing if we can't visualize them being violated and protected and actualized.



In 1971 a fascinating documentary was made about the right of persons with psychosocial disabilities to live in a communal setting. The film was called *Asylum* (2004). But this was something of a departure from the prevailing asylums such as Bridgewater. Made by the Canadian director Peter Robinson and cameraman/editor, Richard Adams, the film documented an experimental project called the Archway Community set in an East London row house. Here, for six weeks, the filmmakers observed the everyday life of its residents struggling with various sorts of mental issues including schizophrenia.

The experimental therapeutic community of Archway was founded in 1965 by the radical psychiatrist R.D. Laing and his colleagues.<sup>17</sup> The idea was to have patients and therapists live together with as little rules as possible and no medication. Laing firmly rejected the medical (and prison) model of mental illness, and believed that only if patients could be responsible for their own actions and decisions, would they make therapeutic progress. Laing and his colleagues were part of a movement that questioned the existence of mental illness. For Laing, mental distress was the result of socialization, and especially the pressures of the nuclear family, which led to what he called the "divided self" or a split between the secure self in the world and another self slipping away and suffering from "ontological insecurity".<sup>18</sup> Once removed from the family, Laing thought that mental distress could be valued for its cathartic and transformative potential. Although Laing never denied the existence of mental illness, his approach was to treat mental distress as a kind of shamanic journey of the self.

This all sounds a bit cosmic and steeped in the counter-culture of the times. But in practice, Archway was real and a fascinating chance to treat mental disabilities with care and concern and empathy. There's an early scene in the film when one of the resident therapists, a relatively young and handsome man in a turtleneck sweater, is introducing the house to a young women with blue eye shadow and looking very mod. They're sitting in front of a burning fire as the therapist explains that the rent is due every Monday and everyone must pay their share for food. Other than that, he adds, there are no other rules in the house.

But he goes on to explain the situation: "There are some people here who were in the mental hospital and found that it didn't help them and they couldn't find anywhere else to live. And so they're here because of that reason and they find that they can live here and it's not a hospital and it's not set up like a hospital. And there's some people who felt like they might have to go into a hospital and didn't want to and that's why they've come here. And then there's people who haven't been in a hospital, they're not going to a hospital, but they're interested in this kind of life people live here." (ASYLUM, 2004).

It takes a few viewings of the *Asylum* to really know for sure who is a resident, who is a therapist, who is a live-in psychiatrist, and who is just a visitor. During the six weeks of filming in the spring of 1971 there were about 18 people in the house, and a few minutes into the film, Robinson's small crew is introduced at a gathering while they begin filming and recording sound. Some of the residents present themselves here as well, including a few who stand out in the film such as David, a middle-aged intellectual who speaks in a flood of coherent and incoherent language and is prone to staging fits. Then there's an ethereal beauty named Julia, looking like a folk singer in her black dress and long blond hair. She delicately introduces herself saying that she can draw, paint, and play the guitar.

The house itself is a complete antithesis of the hospital at Bridgewater. There's actual beds, throw pillows on the floors, several pets in the house, and a large communal kitchen. The residents are seen cooking together, sitting around smoking cigarettes, quietly reading, talking on the phone, having a picnic in the back yard, washing dishes, and having a cup of tea. None of this is exceptional except that these very people are struggling with serious mental issues and from films like *Titicut Follies*, one could imagine that these same folks could be in a totally different environment with cellblocks, tranquilizers, electroshock, and lobotomies. There's also the everyday struggle and caring for each other. Residents comfort each other after breakdowns, someone needs to help Julia down the stairs, another person needs help going to the bathroom, and the collective group has to problem solve serious issues. It's clear from the film that the residents themselves have to be as much caregivers as recipients of therapy. R. D. Laing himself used to remind students that the word "therapist" is derived from the Latin and means to be fully present, to listen, observe with care, and serve with compassion and patience.<sup>19</sup>

The title of the film *Asylum* suggests the kind of places that we associate with this word today. But again, the original usage of the word, and Laing's intention with it in his therapeutic communities, was to evoke a shelter, a place of refuge, and safe space. These ideas in themselves are fundamental human rights especially for persons with disabilities. A film crew could potentially upset this delicate balance. But here one gets the sense that the community trusted Robinson and his team. No one feels

exploited and no one seems to be performing for the camera. After studying this film at length, I feel like the shattering breakdowns and tense crisis situations in the film would have occurred with or without the camera. Peter Robinson himself passes in front of the camera from time to time and even has a couple of conversations with residents. This slight reflexive touch seems just right to expose their presence in the house and does not diminish the team's elegant style of observational filmmaking.

*Asylum* is considered today a classic documentary of its time and it seems to get better with age.<sup>20</sup> The document also recalls a wistful moment when alternative and humane options for healing were introduced against societal pressure to incarcerate and hide those with disabilities. The film also raises questions about the difference between those who are deemed "sane" and those who are considered "insane." The therapists, who advocate on behalf of residents to remain in the house, and try to convince their families to allow the residents to make their own decisions on placement, are very careful not to offer any diagnosis and use inclusive language that suggests that they too might be suffering. These bonds of empathy seem fascinating today when there's such a rush to diagnose learning and emotional disabilities and prescribe prescriptive drugs for any kind of alleged learning or behavioral disability.

The shift from incarceration and brutal mistreatment at Bridgewater and what was happening inside Archway evokes an important tenant of human rights for persons with disabilities. Everyone has the right to self-determination and self-knowledge. And everyone has the right to safety and peace. These were not theoretical ideas in this film. And while six weeks in Archway does not prescribe any kind of cure-all, it does suggest an alternative vision of rights realized and actualized.

At the end of the film, one of the medical volunteers visiting from the States who is struggling with David's outbursts and aggression confides with one of the resident therapists that it's possible to get lost in Archway. The therapist thoughtfully replies: "Yes, we tried to create a scene here together, that if someone needs to get lost then that can happen in as good of circumstances as necessary. And someone has to lose oneself to find oneself. The emphasis isn't so much on one person having the responsibility of being available to someone else—to talk to, to grapple with, or have therapy with. It's as much as the creation of an ambience, a group, a network that can facilitate someone finding themselves, being themselves, and finding out who they are and who can tolerate the vicissitudes of feelings and behavior that we all go through at different times of our lives especially in critical times when one of us is freaking out. And it seems to take a great deal of effort although what were aiming at is something quite hard to achieve, this simplicity, in terms of being with a person, caring for a person, being concerned." (ASYLUM, 2004).

There's something about this film that's quite simple but immensely moving. And it's hard to put my finger on it. Perhaps it's that someone struggling with mental health can stand out on the street and talk to neighborhood children, take a walk down the street, and go across town in the bus. That kind of freedom should never be taken for granted no matter what mental or physical condition we live with. The words human rights are never mentioned in the film. But *Asylum* is not one of those documentaries illuminating a troubled place in the world, it's rather one of those critical turning point films that show us that another way is possible.



In 1971, a young Japanese filmmaker challenged a group of people with cerebral palsy (CP) to hit the streets in order to take action.<sup>21</sup> Kazuo Hara had never made a film before but he was already an activist of sorts for persons with disabilities. As a school aid for “handicapped children,” as they were called then, he would take his students into the streets in their wheelchairs, which would create quite a scene. People would just stop and stare. In the early 1970s, it was a rare for persons with disabilities to be seen in public yet alone a group en masse in wheelchairs. As their adult chaperone, Hara would refuse to help his students in the streets, which forced them to negotiate with the public themselves. It wasn’t just that the Tokyo infrastructure was not accessible to wheelchairs. It was a much larger question about what “disabled” meant in Japan and the line between confinement and physical freedom.

When Hara met an adult group of cerebral palsy activists in Yokohama called the Green Grasses, he befriended them and slowly convinced them that they too had to go into the streets—without their wheelchairs. Only then would people be confronted with their bodies. As a group, they agreed that wheelchairs were part of their physical confinement that shielded their bodies from society. Together, the group with Hara agreed to make a collaborative film with no plan except that they would take “actions” in public spaces. And they wanted to make a different kind of film from the so-called “social welfare” documentaries that directed a sympathetic gaze on the persons with disabilities from a distant and privileged position. The group decided to make something much more radical, something straight from the streets, and they were not interested in pity or even empathy. They wanted change.

*Goodbye CP* (1972) (sometimes known as *Sayonara CP*) opens with the two leading activists of the film, Yokoto Hiroshi and his friend Yokotsuka Koichi hitting the streets in their own special way. Yokoto cannot walk so he devised a way of sliding along on his knees, a kind of lurching forward, his body twitching, pushing off with his arms, and constantly picking up his oversized glasses that are always falling off. The sight of an adult man literally crawling across the busy intersection at a red light astonished people in the street, brought everything to a standstill, and began to actualize the crew’s mandate for the film: “How can we make society accept our existence?”

Meanwhile Yokotsuka rambles along with a kind of zigzagging walk, arms flailing in every direction, his head jerking from side to side. But He has a 35-mm camera strapped around his neck and he’s stepping into the crowds to take pictures of the so-called “healthy” people. Hara convinced Yokotsuka that he had to shoot his pictures very close, within one meter of his subjects. Yokotsuka admitted that photographing complete strangers was initially terrifying but also liberating. The strategy of using another camera in the film created a “reverse gaze” whereby the dominant position of viewing others in the film would be complicated and reflexive.

Throughout the film, several street actions are staged, such as Yokoto sitting in a public walkway with a bullhorn declaring: “We might be killed tomorrow. We want to live freely as human beings.” Hara’s camera circling around Yokoto creates a spectacle itself and people stop to see what’s happening. Eventually people (mostly women) give pocket money to their children so they can donate. Hara breaks his

observational mode and asks them why they felt compelled to give money: “Some people are so unfortunate (...) Because they’re helpless (...) I just wanted to help people in need (...) My child felt sorry for them (...) I feel so bad for their bodies (...) My child is in good health so I feel blessed (...)” (GOODBYE CP, 1972).

*Goodbye CP* is radical film in many ways but it’s also shockingly beautiful. Despite the stereotypical responses by the adults, the shots of the children, running back and forth from their parents, silhouetted with starbursts of sunshine are stunning. But it’s the film’s rawness that compliments its subject matter. The film was shot with grainy black and white stock, on 16mm, with a camera that had to wound up every 40 seconds.<sup>22</sup> Having never made a film before, Hara didn’t bother much with synchronized sound. Thus the overall sound design is a mix of street noise and people talking above and against the images. The team also decided not to subtitle the film forcing Japanese viewers to become accustomed to how people with cerebral palsy speak. Even more disconcerting was Hara’s angles and hand-held camera movement which were as restless as his fellow activists. And his brash editing style, done collectively with the Green Grasses team, displays such a fresh and gritty approach to filmmaking that *Goodbye CP* is considered today a seminal work of avant garde filmmaking as it is a landmark political documentary. Hara would later call his films “action documentaries” because they provoked change.

One of the most uncomfortable sections of the film is when Yokoto is fighting with his wife Yoshiko who also has cerebral palsy and Hara brings his camera into the their home documenting the anguish of their conflict. Hara would go on to make other films that crossed the ethical boundaries of the family and this stark portrayal of domestic rage was shocking for Japanese viewers. While they’re fighting, the team gathers in another room debating the merits of continuing with the project and dismissing Yoshiko’s belief that they’re just humiliating themselves further by the film.

The degree of reflexivity here makes the inclusive format of the film ever so real and taps into another fundamental human right. Everyone has the right to self-expression. And everyone has the right to represent themselves. Everyone also has the right to privacy. And the mixture of these rights clashing with each other makes *Goodbye CP* a truly transgressive film, edgy in its stark realism. But it’s also a collective project, and the crew present themselves not as victims but as participants. Today, participatory media platforms are all the rage in human rights, and *Goodbye CP* was on the vanguard of this movement.

More street actions happen in the film and one in particular brings on police intervention. The police call the protests a freak show but the team deems the intervention a critical success since they’ve created such a public nuisance. Yokoto later reads his poems in public, draws a chalk circle around himself where he sits, and writes: “You who have legs to stand, you who forbid me to walk, this is how you keep your legs, and all the people around me, all the legs, for what reasons do you forbid me to walk?” And in one famous scene, Yokoto takes off his clothes in the middle of the street, with no shame, forcing people to look at his body. In the end, Yokoto crawls away on his knees lamenting whether the film has done any good. My reading of this final scene is that he’s fighting as much against the prospect of death than his disability and this struggle links him with that common destiny that awaits us all.

*Goodbye CP* was not exactly a hit when it came out in 1972. It was scandalous. The public accused Hara of humiliating people with cerebral palsy and making a public spectacle of their struggles. They didn't know however, that public performance was the point because it was activism and resistance. Nor did they initially understand the participatory ethos of the film and how the space was collapsed between the filmmaker and his collaborators. But those with cerebral palsy loved the film and they understood everything people were saying without subtitles. They even got all the inside humor that the general public missed in the film. Yokoto Hiroshi became something of a folk hero for persons with disabilities in Japan. And in time, public sentiment began to change recognizing the singular beauty and courage of the film. Today, the film is required viewing in Japan for all students studying anything to do with disabilities. It's also a cult film for students of avant garde cinema. I use the film in my human rights and media classes to illustrate how activism, participatory media, and poetics can be fused together.



One of the questions in *Goodbye CP* was, what exactly does it mean to be human? Especially when someone is different. Never was this existential dilemma explored with more grace and wonder than in Werner Herzog's 1971 film, *The Land of Silence and Darkness* (2005). At the time, Herzog was a young filmmaker and this was almost a personal project, reputedly made with only a few thousand dollars and a small crew. The entire film has a feel of autumn in Germany with those melancholic pale colors that only films of the early 1970s seem to possess. Like many of Herzog's early films, it's ponderous, almost meditative at times, demanding prolonged concentration on the metaphysical questions that linger with each long take.

The film follows a 56-year old woman named Fini Straubinger who is deaf and blind. As she travels around Bavaria on behalf of the League of the Blind, she meets and helps others who share a similar fate. In fact, she calls them "comrades in fate" who need liberating. But unlike those who were born deaf-blind, Fini took a devastating fall down the stairs as a 9-year old child and in a matter of a few years; she lost all sight and hearing. During this time, she was bedridden for nearly 30 years. Finally, she rejoined society and wanted to help as many people as she could.

In one of the early sections of the film, Fini and her friend Juliet who is also deaf-blind take a small plane ride. It's the first time either of them have ever flown and the look on their faces in the air is nothing but pure bliss as they fly over the snow-covered mountains and reach for each others hands to sign back and forth by tapping and drawing the alphabet across their palms. They're accompanied by a "companion" who does not have a disability but can sign and translate what he sees. It's an unforgettable scene in the history of documentary film and every time I ask someone if they've ever seen *The Land of Silence and Darkness*, they always mention this sequence with awe.

There are other notable sections of the film that approach the experience of being different with nothing but joy. There's a visit to the botanical gardens when a large group of deaf-blind are guided through the cactus plants, each person with their companion translating, and they marvel at the sheer touch of the plants. Even more magical is the visit to the zoo as the deaf-blind hold animals in sheer delight. At Fini's birthday, she warmly greets everyone, speaking out loud for all the companions to

translate, touching her guests, clasping hands, signing, hugging old friends, genuinely asking about their companions who she also knows.

At the party, she asks for a poem and Juliet stands up and announces:

*Please translate for the deaf-blind. I will tell you a poem reflecting on your situation.*

*The title is: The Most Wonderful Art.*

*to stay apart*

*when others have fun*

*by being happy all the time*

*gladly carry out*

*the most sacred task*

*renouncing in a noble way*

*ones personal desires*

*living in darkness*

*from the sun*

*but shining like a star*

*that is art*

*that only one whose soul*

*is bent on heaven*

*can understand*

(THE LAND..., 2005).

The title of the film comes from Fini herself as she describes those who struggle to communicate with others. And it's this darker side of the film and her advocacy work among the deaf-blind that makes this story such a deeply felt human rights representation. Finally, we're at the point in these foundational films where persons with disabilities themselves are in the primary care-giving role. As Fini travels to meet others, their lonely stories are heartbreaking. More than that, they make us wonder how can someone live without communication? But *The Land of Silence and Darkness* is not a sad film. Fini's presence is steadfast as she approaches each situation with nothing but compassion and understanding.

Among those she meets is a certain man-child named Vladimir, age 22, but looking like a boy in his blue V-neck sweater sitting on the floor blowing bubbles and mumbling to himself. He never learned to walk, yet alone communicate, and his life has been lived in one long fog. As with everyone she meets, Fini caresses his face, touching his eyes and ears and places his hands on her face to let him know that she too cannot see or hear and that they're alike. As she begins to teach him some introductory signings on his palm, he seems to awaken, senses some chemistry between them, and digs his fingernails into her palms in a desperate act to communicate. He's shaking back and forth; his eyes are rolling, as he realizes this meeting is something different. When Fini places a portable radio in his lap, he's transformed. Hugging the radio and putting his face to the speaker as if he's listening to the music, he feels the vibrations and senses something magical. Fini surmises that his main problem is that he's bored and that he has the potential for much change.

We meet another deaf-blind child learning how to swim and there's a scene when he's wading in an indoor pool and his teacher lets go of his hand, and the boy reaches out for him. The outstretched hand here is symbolic, so fragile, of this innate need for

human contact. Herzog barely says a word in the film, just a few lines here and there to help introduce people but his camera style is mainly patient and observational. He lets these scenes just run their course which is the opposite of the cut-up style of *Goodbye CP*. This strategy of the long take without cutting recalls the transcendental cinema of so many East European directors and it's what lends this film its poetic aura. This same boy later takes a shower by himself, which is also something new for him, and once he figures out how to handle the rush of steaming water cascades over his body. The scene is another stopper in the film because it's an expression of pure tactile sensuality and it reminds us of how mysterious such an everyday act can be.

But it's the adults that Fini meets where one can interpret the title of the film literally. We meet a 48-year old deaf-blind woman sitting alone in an asylum in a black dress. She's in a cafeteria surrounded by other women who must also be blind or with psychosocial disabilities because they're just sitting there quietly staring straight ahead. It's a strange picture but Fini arrives and instantly humanizes the meeting. As explained, the woman used to know Braille but she has forgotten it and no one wanted her and she ended up at the "neurological clinic" all alone and completely withdrawn from everyone. She hasn't talked to anyone in years and as Fini touches her, she too seems to sense a kindred spirit. Fini takes her hand and begins to trace letters on the table and takes a Braille board and begins to teach her how to use it again. The staff at the asylum marvel that the woman keeps looking at Fini. Herzog closes this section with an inter-title: "When you let go of my hand it is as if we are a thousand miles apart."

The film closes with 51-year old deaf-blind man living with his mother in a home for the elderly. Fini remarks on meeting him that he seems to have dropped off the earth, he's so disconnected. He was deaf by birth but lost his sight at age 35 and has since forgotten how to speak and write. Although, his mother says that a few years before he stepped outside in the winter and reached down and exclaimed: Snow! At one point he felt so rejected by society that he lived with cows for a while in a stable.

They're sitting outside in a courtyard. Fini touches his face and makes contact and begins to communicate with him by signing on his palm. He senses her touch but still seems unmoved. The wind is blowing in the trees and while they're talking about his condition, he gets up and wanders across the yard. It's an autumn afternoon, and as he's walking he runs into some low hanging branches that he follows to the trunk of a tree. There he embraces the tree, hugs it, feels the bark, follows the larger branches, and finally bends over to pick up the fallen leaves. It's a remarkable bit of filming. And Herzog has said that the entire film was meant to lead up to this final moment when this primal connection to nature is made.

The *Land of Silence and Darkness* is a deeply ethical film, with much humility. To interpret it through the lens of human rights is to state the obvious. The *Darkness* is not the specific impairment. It's about the lack of understanding, the ignorance, and the mindset that wanted to let these people disappear without human contact and love. It's that same darkness at Charenton, Bridgewater, and the larger society outside of Archway. It's also all those people who didn't want to see people with cerebral palsy on the streets in Japan. The *Silence* is the silence of society that allowed these things to happen. These five films were foundational because they first broke the silence. They stand out because they were also works of art. They were also transformative

documents in human rights witnessing because they started the change process.

Many filmmakers today continue to represent persons with disabilities and they keep the struggle alive. But all of them are beholden to these astonishing films. To be sure, there would be no international transformation in disability rights and new normative standards of human rights for persons with disabilities without our visual recognition of these issues. This visualization begins with these five films that showed the sorrow, the violence, the rejection, the resistance, and the hope of changing how we perceive those with disabilities.

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## NOTES

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1. This quote is from a chapter about Peter Brook and the history of avant garde theatre (INNES, 1993).
2. For a detailed study of this idea of empty space, see: Brook (1995).
3. See the account of Brook's theatre openings in the 1960s in: Innes (1993).
4. For more on Artaud's thoughts on how theatre effects audiences, see: Artaud (1994).
5. My reading on the generations of human rights is taken from: Reardon (1995).
6. For a historical timeline on human rights of

persons with disabilities, see: <[http://www.hrea.org/index.php?base\\_id=152](http://www.hrea.org/index.php?base_id=152)>.

7. Please see the timeline on disability rights: <[http://www.hrea.org/index.php?base\\_id=152](http://www.hrea.org/index.php?base_id=152)>.

8. One particular website, breaks up all films about disability rights by theme: <<http://disabilityfilms.tripod.com>>.

9. I draw my conceptual framework approach for human rights from <<http://www.pdhre.org>>.

10. There are many articles about the circumstances at Bridgewater State Hospital during the filming of *Titicut Follies*, see: <<http://reason.com/archives/2007/11/16/let-the-viewer-decide>>.

11. For an overview of the history of this film and the legal issues, see Toby Miller's essay on Wiseman: <<http://www.mcc.murdoch.edu.au/ReadingRoom/7.2/Miller2.html>>.

12. For an overview of the Convention and the actual articles, see: <<http://www.un.org/esa/socdev/enable/rights/humanrights.htm>>.

13. To see the U.N. Convention against Torture, see: <<http://www2.ohchr.org/english/law/cat.htm>>.

14. To read about the case in Paraguay, see: <<http://www.disabilityrightsintl.org/work/country-projects/paraguay/>>.

15. To see the video submission on the case in Paraguay, see: <[http://www.witness.org/index.php?option=com\\_content&task=view&id=227&Itemid=60](http://www.witness.org/index.php?option=com_content&task=view&id=227&Itemid=60)>.

16. The homepage at the U.N. for this treaty can be found at: <<http://www.un.org/disabilities/index.asp>>.

17. For more R.D. Laing, see his Wikipedia Page: <[http://en.wikipedia.org/wiki/R.\\_D.\\_Laing](http://en.wikipedia.org/wiki/R._D._Laing)>.

18. To read more of Laing's ideas on the divided self, see his book (LAING, 1969).

19. Taken from the remarks by Kenneth Robinson at the opening of *Asylum* at the Museum of Modern Art in New York in 2010: <<http://surveillancefilms.com>>.

20. See the review of *Asylum* by J. Hoberman, one of the most esteemed film critics working today: <<http://surveillancefilms.com>>.

21. See the book *Camera Obtrusa* by Hara Kazuo and his chapter on the history of making the film *Goodbye CP* (KAZUO, 2009).

22. Please see the chapter on the making of *Goodbye CP* (KAZUO, 2009).

## RESUMO

Não haveria mudança transformacional nos direitos humanos para pessoas com deficiência sem a existência de sua representação visual. Este artigo examina cinco documentários dos anos 1960 e início dos anos 70 que iniciaram a visualização das deficiências. Descrevendo os filmes e refletindo sobre as mudanças em relação aos direitos das pessoas com deficiência, o artigo objetiva situar a Convenção das Nações Unidas sobre os Direitos das Pessoas com Deficiência dentro da rica história da prática documental.

## PALAVRAS-CHAVE

Documentários – Direitos humanos – Pessoas com deficiências

## RESUMEN

No habría ningún cambio transformador en los derechos humanos de las personas con discapacidad sin el papel de la representación visual. Este ensayo examina cinco documentales fundacionales de finales de la década de 1960 y principios de la década de 1970 que hicieron posible visibilizar las discapacidades. Al describir las películas y reflexionar sobre los cambios en los derechos relacionados con la discapacidad, este ensayo procura ubicar la Convención de las Naciones Unidas sobre los Derechos de las Personas con Discapacidad dentro de la rica historia de la práctica documental.

## PALABRAS CLAVE

Películas documentales – Derechos humanos – Personas con discapacidad