The Right Not to Work: Power and Disability

by Sunny Taylor

I have a confession to make: I do not work. I am on SSI. I have very little work value (if any), and I am a drain on our country’s welfare system. I have another confession to make: I do not think this is wrong, and to be honest, I am very happy not working. Instead I spend the majority of my time doing the activity I find the most rewarding and valuable, painting.

The very first thing that people ask me when I say I am a painter is “Do you sell your work? Are you supporting yourself?” I actually do sell my work, but I do not support myself from these sales. I hate this question and I feel ashamed no matter how I answer it. This is because I always feel like this question is a test; a test to see whether my lifestyle and hobby are legitimate; and money is the gauge of this legitimacy. Is money really where all value lies? Are my art and my lifestyle really less meaningful because I do not support myself financially?

Due to my disability (arthrogryposis multiplex congenita), I paint holding the paintbrush in my mouth instead of my hands; I use an electric wheelchair for mobility. When I first realized that due to my impairment I might be unable to work in a traditional job, I was worried about my financial future, but it never occurred to me to worry about my life’s value as a “nonproductive” citizen. However, I think that I am unusually fortunate to have been raised with a belief in my own inherent value, because many disabled people seem to carry a deep “non-working guilt,” even if they are successful in other areas.

This became even more apparent to me last September, when I participated in my first protest for disability rights. The event, a two-week, 144-mile march from Philadelphia to Washington, D.C., was organized by one of the disability movement’s most prominent groups, ADAPT (American Disabled for Attendant Personal-care Today). ADAPT has been at the forefront of disability rights for over twenty years. This was not only my first action, it was also my first time to be completely surrounded by other disabled individuals. At first I was very intimidated. However, once I got beyond the panic of camping out in parking lots and traveling on the highways with two hundred of the most physically challenged individuals I’d ever met, I decided to use the time to research the disability movement and to hear other disabled people’s perspectives. There
were two points that came to fascinate me over the course of the march. The first was simply the lack of press our efforts received (we were barely mentioned by national news and virtually ignored by the left-wing media). The second was more subtle; it was the guilt I realized many activists felt for not working, even amongst those who were physically unable to have what could be considered a regular job.

Before they came to focus on institutionalization, ADAPT was at war with the public transit authorities. ADAPT (originally American Disabled for Accessible Public Transit), started as a project of the Atlantis Community in Denver, Colorado, in 1983. Their goal was to make public transportation accessible to persons with disabilities, so that those people who had managed to live outside institutions could also participate in their communities. For seven years ADAPT blocked buses, closed off streets, and participated in numerous other forms of civil disobedience across the United States, to protest for the right to ride. ADAPT’s peaceful direct action demonstrations eventually paid off when they helped to pass the Americans with Disabilities Act (ADA) in 1990, which requires that public transit be accessible. Clearly the next issue to fight for was attendant services, so that there would be more disabled people living independently in their own communities who would have the freedom to utilize the new lifts.

And that is what the September march focused on: the “stolen lives” of the nearly two million people who are currently “warehoused” in nursing homes and Intermediate Care Facilities for the Mentally Retarded (ICFMRs). Over two hundred of us in our wheelchairs went the 144 miles, from the Liberty Bell to Capitol Hill, to protest for the passage of the Medicaid Community Attendant Services and Supports Act (MiCASSA), which would provide in home care for those who are now stuck in nursing homes. America has over 17,000 nursing homes, two-thirds of which are for-profit ventures. MiCASSA would allow people to decide how their individual Medicaid dollars should be spent, instead of funneling them into the $70 billion nursing-home industry. On average it costs $9,692 annually to provide someone with Medicaid Assistive Services. However, the national average annual cost to house one person in a nursing home is $40,784 and the standard of services in these institutions is often shockingly low. There is often a high incidence of physical and sexual abuse, as well as negligence to hygiene and psychological needs. Even at best, individuals are still stripped of countless freedoms people on the outside take for granted—such as choosing when and what to eat, when to sleep, and even who to talk to.
Despite the fact that two million people are denied the privilege of determining where and how they live and who cares for them, the lack of press garnered by our two-week trek (and on disability issues more generally) does not exactly constitute a mystery. Disabled people are regarded as disadvantaged citizens, and so this fact is not news in itself. Disability is most commonly perceived as a personal tragedy, isolated and spontaneous, and so rarely worthy of a second thought let alone headlines (unless as a human interest story). Disabled people are far from enjoying the advantages of social or economic equality, but the point is that they are far from even being seen as a deserving identity group. While issues regarding racial, gender, and sexual orientation equality are all at the forefront of political and social theory, disabled people are almost always left out of these conversations. The disabled are viewed with sympathy as victims of “bad luck” who will simply have to accept disadvantage as their lot in life, not as an identity group that is systematically discriminated against. Unlike sexism and racism, which are perceived to be significant social problems, disability falls under the social radar and disablism is not recognized as a damaging or even particularly serious form of prejudice.

The idea of disability as something to pity is highly damaging to our cause. As a physically challenged individual who enjoys and is grateful for her body and her life, this view of my situation is offensive and presumptuous. Unfortunately, it seems to be the dominant way in which disabled individuals are still seen. Without a doubt, many strides have been made over the last thirty years, such as improvements in disability legislation and equal access laws, thanks to the work of civil rights advocates. But despite these tremendous advances, disability remains a fringe issue. Of the many social movements that became visible during the sixties and seventies (civil rights, women’s liberation, gay rights, and environmental advocacy, among others) disability movements rarely merit a mention. It may seem glib, yet part of this willful ignorance of disability politics may stem from the simple fact that impairment is perceived as neither cool nor sexy. This lack of “cool” is a hard thing to fight, since it is hard to ever foresee disability as becoming fashionable like many movements that have been co-opted by that holy of U.S. holies, marketing. We have black-power afros on models in ads and the phenomenon of “girl power” as the latest marketization of feminism; it is next to impossible to picture a wheelchair or incontinence becoming the next hip iconography. Of course, the point is that it shouldn’t have to be. If people are sincere in their praise of equality and difference they will have to get over finding some differences “cooler” and more praiseworthy than others.
One fact that makes disability so hard to understand is that there is no single model of disability; the human body can be impaired in an almost infinite number of ways, and people of all walks of life can become impaired. "As with the population as a whole, disabled people are characterized by difference rather than normality: differences in terms of gender, minority ethnic background, sexual orientation, age abilities, religious beliefs, wealth, access to work and so on. Clearly, their situation cannot be understood or, indeed, transformed by any theory or policy which is based on conventional notions of normality and the existence of a single set of culturally dominant values." The only thing impaired people have in common is their political disablement and the economic, behavioral, and emotional similarities that impairment can cause. Disability, partly as a result of this intense differentiation of those people affected, may be the only branch of the civil rights movement that cannot be appropriated. Disabled people are an example of a movement and identity whose image and capabilities are infinitely various. This variety, however, is what makes us so difficult to incorporate into the modern corporate environment; what changes will need to be made for us, what adaptations, what special accommodations, what costs will be incurred, and what profits diminished?

Despite advances, both in theory and in practice, disability rights remain some of the last to be thought about, and as a result are typically some of the first to be forgotten when it comes time for cutbacks or budget "reform." The disability movement has failed as of yet to convince people that our existence in society is valid and essential. The public remains unconvinced that our struggle is actually theirs as well; advocates for the disabled are de facto fighting for the rights of the elderly, and many of the services they are demanding will help their able-bodied counterparts as well, both directly (for example, when a worker become temporarily impaired or by providing able-bodied individuals with more options as they inevitably age) and indirectly (they may enjoy peace of mind because a loved one is living happily in their own home with the help of an attendant). We have failed to get our point across; but what is our point? Perhaps it is best expressed in the idea that disability is a political issue not a personal one.

Disability theorists make this clear by making a subtle but significant distinction between disability and impairment. The state of being mentally or physically challenged is what they term being impaired; with impairment comes personal challenges and drawbacks in terms of mental processes and physical mobility. To be impaired is to be missing a limb or born with a birth defect; it is a state of embodiment. Being impaired is hard. Without a doubt, it makes things harder than if one is not impaired. However, more often than not, the individual accommodates for this impairment and adapts to the best of their ability. For example, I am impaired by arthrogryposis, which limits the use of my arms, but I make up for this in many ways by using my mouth.
Disability, in contrast, is the political and social repression of impaired people. This is accomplished by making them economically and socially isolated. Disabled people have limited housing options, are socially and culturally ostracized, and have very few career opportunities. The disabled community argues that these disadvantages are thus not due to impairment by its nature, but due to a cultural aversion to impairment, a lack of productive opportunity in the current economy for disabled people, and the multi-billion dollar industry that houses and “cares” for the disabled population that has developed as a consequence of this economic disenfranchisement. This argument is known as the social model of disability. Disablement is a political state and not a personal one and thus needs to be addressed as a civil rights issue.

Viewing disability in a materialistic framework demonstrates how this political repression functions. Take disability theorist Brendan Gleeson’s adaptation of the analysis of Karl Marx, who defined nature as existing prior to and independent of human experience, and yet simultaneously as something that “attains its qualities and meanings by means of a transformative relationship of human labor.” Nature exists outside society as an objective reality, but it is also used and changed by humans to meet their needs. Marx used the notion of “two natures” to describe this historical transformation and he argued that this change was formed through human labor. Almost all of the terrestrial “natural world” has been somehow altered through human intervention, and nature is indissolubly connected to human society. Marx used this analysis of nature to show how the capitalist mode of production “altered nature so as to deny for much of humanity their species potential.” Nature pre-exists social formations, but is itself evolving also, not only due to biological and ecological factors, but also through human intervention. Each human relates to nature through their own physical experience as gendered, as aged, and as abled, and each experience of embodiment should be seen as both historically and socially evolved through natural elements. The body is both a biological fact and cultural artifact; “the former constitutes a pre-social organic base upon which the latter takes form.” Disability activists and theorists see impairment as equivalent to “first nature” and disability as an example of “second nature.”

Marx and later theorists have shown how capitalist development has privileged certain biological forms of embodiment (for example white able-bodied males). Because of this, it is important when trying to understand the impact of space on bodies (for instance inaccessible buildings and transportation), to consider who is forming (and has formed) spaces and who inhabits them. The extreme inaccessibility and alienation felt by impaired people may not be a natural consequence of their own personal embodiments in the twenty-first century, but instead a complex system of historical, cultural, and geographical discrimination that has evolved inside and alongside capitalism and that we now simply regard (and too frequently dismiss) as disability. Crippled and elderly people have an especially precarious relationship to the machine that is production and
consumption. People work hard, they age, their efficiency inevitably lessens and, unless they are fortunate enough to have some savings stashed away, they are too often put in nursing homes where their new value will be as “beds.” As Marta Russell has astutely pointed out, the institutionalization of disabled people “evolved from the cold realization that people with disabilities could be commodified... People with disabilities are ‘worth’ more to the Gross Domestic Product when occupying a bed in an institution than when they’re living in their own homes.”

Gleeson argues that with the transition from feudalism to capitalism, impaired people became unproductive members of society and thus disabled. The rise of commodity relations profoundly changed those processes of social embodiment that originated in work patterns. In particular this political-economic shift lessened the ability of impaired people to make meaningful contributions to their family and households. Markets introduced into peasant households an abstract social evaluation of work potential based upon the law of value; that is to say, the competition of labor-powers revealed as average socially necessary labor times. This productivity rule devalorized the work potential of anyone who could not produce at socially necessary rates. As households were progressively drawn into dependence upon the competitive sale of labor-power, their ability to host “slow” or “dependent” members was greatly reduced.

Due to the social arrangement of peasantry in medieval Europe, impaired people were commonly integrated into the economic and social system, Gleeson explains. “The feudal peasantry was characterized by a relatively intimate union between domesticity and labor,” which allowed for the social use of the various skills and abilities of the impaired. Most of the impaired lived with their families and did contribute to their household’s economy. Due to the self-sufficient economy of feudal society each member of the household had to contribute some form of labor so as to balance out their own needs. Because of the abundance of jobs that needed to be done to keep a household fed and warm, it was almost always possible for an impaired member of the house to contribute. It seems the concept of the helpless had not been invented yet, and challenged people were expected to contribute what they could. “The material context of feudal production allowed peasant households a great degree of liberty in designing everyday tasks that would match the corporeal capacities of each family member.”

This is not to say the feudal era was a utopian time for the impaired, but instead is an attempt to demonstrate that our current conception of disability and the position of the disabled are not absolute and should be challenged and changed. In contemporary American rhetoric there is a strong emphasis on independence and self-sufficiency. America is the country where everyone has the opportunity to become “independent.” A person, if strong enough, can lift herself up by her bootstraps and own the American dream of a nice new car, a big house, and a
good retirement plan; or better yet, she can live the new American dream and become rich, famous, and beautiful. Independence is perhaps prized beyond all else in this country and for disabled people this means that our lives are automatically seen as tragically dependent. Michael Oliver, like many disability theorists, argues that dependence is relative. We as a society are all dependent on each other. The difference between the way the disabled community sees dependence, and how the rest of society views it, is that there is not so much emphasis on individual physical independence. “Professionals tend to define independence in terms of self-care activities such as washing, dressing, toileting, cooking and eating without assistance. Disabled people, however, define independence differently, seeing it as the ability to be in control of and make decisions about one’s life, rather than doing things alone or without help.”

Today, independence is more about an individual being in control of their own services (be it education, plumbing, electrical, medical, dietary, or personal care), than it is about an individual being completely physically self-sufficient; this is true not only for the disabled population, but for the population in general. This ideal of physical self-sufficiency is a byproduct of the rhetoric of economic self-sufficiency. But no one partakes in American capitalism independently; there is no such thing as a “self-made” individual. In this respect, able-bodied people should take a second look at the position of disabled people; perhaps, ultimately, their position as interdependent is not so at odds with the position all able-bodied people occupy.

A huge part of the stigma attached to being disabled is that due to disabled people’s physical dependence, they are seen as burdens (because they can’t work according to our current standardized economic system). The more impaired someone is the more of a burden they are. In actuality, the only reason that many people are a burden on their family and friends is that they have such limited options. People who try to live independently with the help of loved ones often find that it is next to impossible because the state has no independent living options and so the burden is indeed too great to take on individually. Thus many people, simply due to financial constraints, have no other option but to be put in an institution. In our society it is not the impairment that is the only reason for dependence; it is our impaired system of social services. In my life I have experienced both extreme physical dependence and relative physical independence. I spent years as a preteen trying to figure out how to dress myself and take myself to the bathroom. This was out of a complete conviction that if I were not physically independent I would forever be a burden on my family and that I’d never be free to have my own life. Because of the way the personal care system is set up now, it is true that being physically self-sufficient in these matters has made my life easier simply because I do not have to worry about institutionalization or fighting for a personal care attendant. However, my life has not changed that dramatically with the ability to pee or change my clothes when I want to, and I have since realized how little it affected my ego or my daily routine.
The issues that caused me worry during this period were not things that directly were caused by my physical limitations (I was not embarrassed by needing help), but were indirectly caused because of the stigma others attached to needing help and by the worry that these physical necessities could lead me into a life without choices.

Much of the empowering rhetoric in disability movements is about becoming employed and about having equal access to mainstream society. Capitalism has at it root the idea of an individual's worth being intrinsically linked to their production value. Many, though by no means all, disabled people will never be good workers in the capitalist sense: if you cannot move or speak, it is hard to succeed in a mainstream career. There is a small but significant percentage of the disabled population that has “made it” and has achieved economic equality working as professionals, lawyers, artists, professors, and writers. They are a fortunate minority and the work they do is important. These opportunities have everything to do with class and are not open to all impaired individuals. I, like many people, will never make a good waitress, secretary, factory worker, or bus driver (unless there were massive and expensive adaptations to the bus I was driving), the type of work open to people who lack higher education. It is hard to think of a vocation where my contribution would be desirable in a cost-benefit analysis. The minority of the impaired population that does have gainful employment are paid less than their able-bodied counterparts and are fired more often (and these statistics are more egregious for disabled minorities). To ensure that employers are able to squeeze surplus value out of disabled workers, thousands are forced into dead-end and segregated jobs and legally paid below minimum wage (for example, in the case of “sheltered workshops” for those with developmental disabilities). The condescension towards the workers in such environments is severe. Why should working be considered so essential that disabled people are allowed to be taken advantage of, and, moreover, expected to be grateful for such an “opportunity”?

Disabled people are brought up with the same cultural ideals and ambitions and dreams as their able-bodied counterparts; we too are indoctrinated to fetishize work and romanticize career and to see the performance of wage labor as the ultimate freedom. And yet, for the most part, we are denied access to this fantasy; many of us live on government aid or family support or even charity. If you have a severe disability your likelihood of having a job is 26.1 percent (as compared to a rate of 82.1 percent for working-age non-disabled people). Our largest contribution to the economy is as “beds,” as nursing homes call the aged and disabled who fill their vacancies and bank accounts. Shouldn’t we, of all groups, recognize that it is not work that would liberate us (especially not menial labor made accessible or greeting customers at Wal-Marts across America), but the right to not work and be proud of it? How would this shift in thinking affect the goals and attitude of those concerned with the rights of impaired people or the self-image of those who are impaired themselves?
This is not at all to say that disabled people should cease to be active or that they should retreat into their homes and do nothing (the main problem is already that we are too isolated). The right not to work is the right not to have your value determined by your productivity as a worker, by your employability or salary. Many disabled people, especially severely disabled individuals, do stay home and thus do not work or are held hostage in nursing homes and are denied gainful employment. What I mean by the right not to work is perhaps as much a shift in ideology or consciousness as it is a material shift. It is about our relation not only to labor but the significance of performing that labor, and to the idea that only through the performance of wage labor does the human being actually accrue value themselves. It is about cultivating a skeptical attitude regarding the significance of work, which should not be taken at face value as a sign of equality and enfranchisement, but should be analyzed more critically. Even in situations where enforcement of the ADA and government subsidies to corporations lead to the employment of the disabled, who tends to benefit, employers or employees?

I want to make clear that I am not saying people should stop fighting for equal rights in our current system, but that we should simultaneously think beyond the system in place. Many disabled people want to work and can work, but are discriminated against by insurance companies and employers. It is very hard as a disabled individual to go to college (every school I’ve applied to have discriminated against me despite the ADA), and so the disabled have a hard time competing for better jobs. Another catch-22 is that because better jobs are often better paying they can sometimes threaten our SSI insurance, which for the severely disabled is often the only insurance that will cover essential needs; this encourages more people than you would think to stay out of the workplace. The paradoxes and difficulties and the economic and social challenges of being disabled and living on SSI astonish me daily; still, I remain unconvinced that fighting for equality within the current system (that is, to some extent, the right to be part of the exploiter class as opposed to being part of the exploited) is the ultimate ideal worth fighting for.

Is the goal to be “mainstreamed” into our current society or to change society? As Michael Oliver says: “It is bizarre for people to think that we as disabled people can live in Britain with full civil rights and all the services we need without fundamental changes. We are not actually talking about tinkering around at the edges of society to let people in. For disabled people to play a full part in British society, this society will have to change fundamentally.” Fundamental social change looks like it is a long way off, I’ll admit, and in the meantime we are frequently told the only way to change the system is to participate in it. The more economic and social affluence one has, the more one can maneuver within the system. I am told the way individuals achieve this is through building a successful career, through working. All of this holds some important truth. The first step to equality is independent living and getting people out of nursing homes. Once out of nursing homes, impaired people also need an accessible environment so they
can interact with others who live in their community and share their interests and overcome the problem of geographic and environmental isolation. These material changes (accessible buildings and transit, and independent living) are absolutely necessary for the liberation of the impaired population. Many disabled have in fact fought for a living wage (it was an early disability cause in Britain), a cause worthy of the support of advocates for the impaired and for humanity in general; yet this cause necessarily demands a reevaluation of the role and significance of work and implies a right not to work as well as a right to live.

In a capitalist consumer society where everyone wants the perfect face, perfect job, perfect family, and perfect body, disability will never be appreciated or even fully accepted. In a culture in which the appearance of self-sufficiency and autonomy is essential, the dependence of disabled people (because they do not live up to this myth), may always be reviled or at least patronized. Even progressive institutions and people have discriminated against me more times than I can count. Progressives, like most able-bodied people, are loathe to identify with crippled people and more often than not refuse to acknowledge two simple truths. The first is that they, if they live long enough, will join our ranks. Impaired advocates sometimes joke that people should actually consider themselves “temporarily abled.” We all age and most people end up infirm. It is astounding how little concern there is for the quality of life and the unfreedom of the elderly in this society; I can only surmise that it is the result of a collective coping mechanism of denial. The second fact is that the treatment of disabled people is merely a more pronounced form of the condition of other populations in the contemporary workplace. Many Americans lack affordable health insurance, secure employment, and are also denied the right not to work. The casualization of employment, inadequate wages, the return of many senior citizens to the workforce when they can’t make ends meet after retirement, the lack of paid vacation, the encroachment of the work week on our weekends and evenings, and mounting debt for the poor and middle classes, all evidence a lack of freedom from work oriented activity and anxiety. Working masquerades as the ultimate freedom and the premiere signal of independence, and yet more commonly seems to represent just the opposite of those two ideals.

I remember one time I was in a flea market in Georgia, and a middle-aged toothless woman came up to me from behind her booth and said, “You’re so brave, I would hate to have your life.” I was about thirteen and even then I couldn’t help but smile because I felt the same way about her. I knew that I most likely would have more options open to me despite my disability than she ever had simply due to the educational advantages I have had and due to my unusual background and supportive family, and that I would hate to have her life too. Human beings are so quick to judge other’s existences, but what is even sadder to me is that if people could just take the extra step to see how their experiences are affected similarly, they would most likely find that our repressions share the same roots. What makes my life hard is the same as that which makes the fleam-
market woman's life hard; we are both victims of a society that does not appreciate our value, or values our contributions in a very limited sense.

Considering these fundamental similarities, it is often surprising to me how often disabled people are excluded from leftist politics and media. Many disability movements (including ADAPT) have tried to join forces with other identity groups in the struggle for change. Disability has not made it into the canon of identity politics and as a result is frequently excluded from progressive struggles. We have been ignored and in fact shunned by women's movements (largely based around misunderstanding regarding the issue of abortion), racial movements, gay and lesbian activists, and to a large degree even workers' unions (an ongoing example is the Service Employees International Union, which, in its attempts to save the jobs of its members who work at Laguna Honda, the world's largest nursing home, has argued that impaired people are invalids who must be institutionalized despite protests from disabled advocates).\(^\text{12}\) Sadly, I think this proves that even the most culturally sensitive of people frequently choose not to look past a medical and charitable view of disability. Disability is an obvious example of the need for fundamental structural reform and I am surprised that people who desire change have not more often reached out to our movement. We epitomize many ways in which our political and social systems need to change. We are often born out of war, financial inequality, and environmental degradation. My disability is a birth defect caused by a U.S. Air Force contractor that illegally polluted my neighborhood's ground water. They buried toxic chemicals near our community's wells for over forty years, but did not bother to remedy the situation even after awareness of the damage was raised; most likely this is because the area was inhabited by poor Latino families and residents of a local Indian reservation. Thousands of people died or became impaired due to the Air Force's negligence. Unfortunately, my case is not rare.

Being impaired or not being normal (which, as I have said, with the help of family and technology and with perseverance can be overcome) is not sexy by common standards and neither is dependence. The fact is that impairment reveals our interdependence and threatens our belief in our own autonomy. And this is where we return to work: the ultimate sign of an individual's independence. For many disabled people employment is unattainable. We often simply make inefficient workers, and inefficient is the antithesis of what a good worker should be. For this reason, we are discriminated against by employers. We require what may be pricey adaptations and priceless understanding. Western culture has a very limited idea of what being useful to society is. People can be useful in ways other than monetarily. The individuals who I marched with may not have paying jobs, but they spend hours each day organizing protests and freeing people from lives in institutions. Isn't this a valuable way to spend one's time? Disabled people have to find meaning in other aspects of their lives and this meaning is threatening to our culture's value system. Though education, legislation, and technological developments may work to level the employment field for some
impaired individuals, we should keep some fundamental insights from Marxist economic theory in mind, particularly the theory of surplus value, which dictates that higher profits result from the ability to pay less for labor power than the value imparted by the worker. The same rule that often excludes the impaired from the traditional workplace also exploits the able-bodied who have no other choice but to participate. The right not to work is an ideal worthy of the impaired and able-bodied alike.

Notes

1. The Supplemental Security Income program (SSI) is administered by the Social Security Administration and pays benefits to individuals who are both poor and disabled.
5. Oliver, Politics.
8. Gleeson, Geographies.
10. Oliver, Politics, 91.