DISABILITY

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When Baby Jane Doe, a disabled newborn, made headlines in l984, editorial writers across the country decided that, since her "quality of life" would surely be awful, her parents should be allowed to let her die.

When Elizabeth Bouvia, who has cerebral palsy, had earlier wanted hospital help in starving herself, she too gained headlines—and the sympathy of editorial writers who, again with "quality of life" comments, agreed she, too, should be allowed to die.

Almost no one asked the obvious question: "What is it that has been made so difficult about raising a disabled child in this society — about being a disabled adult in this society — that warrants death?"

In 1987, Nancy Jones, who had been brain damaged seven years before in a car wreck, starved to death because medical personnel removed her feeding tube at the request of her family. This occurred legally in spite of the testimony of two widely respected neurologists that she was able to understand and follow verbal requests and showed other signs of being mentally alive.

Now, as we move into the '90s, the pressure of disability issues is increasing and decisions are less and less escapable as to how the country, small communities, and individuals will respond to people's unequal amounts and kinds of physical and mental ability. The rising proportion of our population who are old, the still-increasing numbers of people with AIDS and ARC, disabled people's recent unprecedented political awareness and group actions demanding justice — these are among the forces pushing disability issues into the awareness of many people who did not feel directly affected before.

BAD LUCK?

The oppression of disabled people is brutal; the Pigs are vicious. Society demonstrates in many ways that it wants people with severe medical conditions at the very least out of sight, and preferably dead. ("I'd rather be dead than crippled for life." "I want to die before I become a burden.") Yet, though evidence of oppression abounds, disability is not commonly thought of as "oppression."

Even politically progressive people, who accurately see many other inequalities as oppressions, persist in assuming that the lack of power disabled people face is somehow intrinsic to their medical condition — a personal, individual misfortune.

One way of beginning to see disability as a human-made oppression — rather than an unfortunate stroke of fate — is to ask oneself whether things aren't being made considerably more difficult for people with medical conditions than they need to be. And the answer is, "Yes."

One thing to notice is that disabled people are kept from earning money by arbitrary rules — rules made by non-disabled society. Because most disabled people are slowed down and have their energy drained in ways additional to the energy-drains on able-bodied people, most do not have energy remaining to accomplish the full-tilt, forty-hour week that our particular economic system generally demands.

Yet most jobs are set up to discourage part-time work. In many institutions part-time work does not exist, and when it does, it usually entails a loss of crucial benefits such as insurance and sick leave. Often there's a reduction in hourly pay, as well.

As a reason for making part-time work unavailable or very unattractive, management cites the increased time and cost of managing more employees. But maybe an unspoken reason is that if part-time work were an attractive option, great numbers of unhappy workers with no health problems or relatively slight health problems would choose to work less than they do now, while people with severe medical conditions would work more than they do now. Then the crucial-to-exploitation lines between able-bodied (useful) people and disabled (useless) people would blur or disappear.

Besides economic barriers, one notices that barriers are literally built into the environment which cause people with disabilities to need more help than is intrinsically necessary; that cause them to waste enormous amounts of physical and emotional energy. And technology routinely applied to help non-disabled people overcome natural barriers like the telephone, is not widely applied for disabled people. Things like TTYs, open captions on television, computer-generated print into Braille and voice output are not routine in our society — though they could be.

Thus, extra help some people need — because of inabilities intrinsic to the specific medical condition rather than inabilities created by the environment — is far less than we have been made to assume. Even so, such help is not available to these people in forms which allow them to retain their power as respectable human beings.

In today's industrial, capitalistic economies, society is fragmented into individual families — often units of one person. In such an arrangement, people with medical conditions are cut off from the varied informal helpers available in a close extended community where many people come and go in a flowing pattern. In the United States today, a few isolated friends or relatives are frequently loaded with huge unbearable amounts of responsibility to sustain disabled persons. This often leads at best to chronically strained relationships, or worse, to the selective abortion of disabled fetuses, killing of disabled newborns, physical abuse of disabled children or adults, and profound anger, guilt and desperation of caretakers.

Help could be available from state-paid helpers, hired and dismissed by the disabled person, who are fairly paid and impersonal, whose help the disabled person therefore does not have to cajole or reward with gratitude, sex, personal interest, or entertainment. At present, state-paid help is very hard to come by. Only very severely disabled people have hope of getting it, and then only in certain states. The money to make this happen could be freed up through a redistribution of resources; the economic, human and natural resources to make it possible are already available.

At the same time our society prevents disabled people from helping themselves economically and physically, and creates circumstances in which sufficient help is difficult to obtain for anybody (let alone someone with disabilities!). It promotes the attitude that to need major help is shameful. Competition and self-sufficiency are idealized; cooperation, though given lip service, is viewed with condescension or suspicion. In such an atmosphere, to need long-term or very intimate help — or to encounter someone who does — causes extreme emotional discomfort.

It rarely occurs to anyone that such an attitude toward giving and receiving help is nothing more than cultural convention.

WHAT WE ARE MEANT NOT TO SEE

If one begins to believe that our society is actively creating and perpetuating disablement for some of its citizens, the next question we must ask is: what might an economic system have to gain from such an arrangement?

Disability presents a unique problem to economic systems based on exploitation. Other groups of people can be exploited as workers — by their race, gender, or class; even non-disabled children are future workers. And an argument given in favor of treating old people well is that they have earned their reward through many years of work. But many people with severe disabilities cannot — and never will be able to, no matter what the accommodation — produce at the pace and in the form required by economic systems geared to generate large profits and privilege for a few gained through using other people. By and large, disabled people are not usable in that way.

What takes a non-disabled person only a short amount of time can take a person with a severe disability much longer — either to do more slowly for themselves, or to arrange for someone else to do because they themselves cannot do it. Far from producing a competitive amount of work, many disabled people require work on the part of other people to stay alive. And the work they require is in such a primal form that it can hardly be ignored the way dependence is ignored in the case of non-disabled people — who are asked in our society to operate under the fragile and anxious pretense that they are self-reliant.

In any economic system that depends on workers who at some level feel — and are — used, over-tired and under-rewarded, those who don't work (unless they are super-rich) must be made to live visibly unenviable lives. People who cannot work “competitively” (full-tilt) must be kept impoverished, isolated, without power, their lives kept miserable enough to ensure they're pitied rather than envied by unhappy non-disabled working people.

If disabled people were commonly seen moving about easily on public transportation, getting in and out of houses and public buildings easily, having access to information, access to paid helpers when help is needed, the opportunity to work as they can, sufficient time to rest, access to money they have not earned to compensate for the limitations in earning power brought on by their loss of endurance; if such disabled people were seen contributing to community life, having friends and being sexy, then no one would pity them or feel guilty in their presence.

In fact, the degree to which non-disabled workers were oppressed would be the degree to which they envied and resented, rather than pitied and feared, disabled people.

Over-work, speeded-up work, unrewarded work, lack of control over how one spends one's work day: all these things would cease to be preferable to the alternative of having a “disability.”

Whether specific medical conditions are “disabling” or not depends almost entirely upon circumstance. A quadriplegic with money, enough helpers, equipment such as vans and lifts, and a group of friends and lovers who are not very encumbered by ableist attitudes is not very disabled. On the other hand, an “able-bodied” worker who sprains her ankle but is without the amount of paid sick leave she needs to stay home and heal, and without the helpers she needs to do chores that have now become exhausting, is fairly “disabled.” But this fluid continuum up and down which all people would normally slide according to their current medical condition and other circumstances is obliterated under a system in which “work,” narrowly conceived, is the measure of worth of an individual.

It is not due to medical conditions, but through specific economic practices, physical barriers, and inculcated cultural attitudes that people are very materially separated into the two camps of “able-bodied” and “disabled.” The first must be willing to do unfairly hard and/or meaningless work without much question or hope for change; the second must be kept powerless and pitiable and their situation feared.

LAYERS OF MYTH

Among the most powerful myths that sustain the powerlessness and low valuing of people with medical conditions is the belief that “nothing can be done” about disability. This myth deserves careful scrutiny because it is too central to the issue — and because it is on the verge of giving way.

On the one hand, everyone grants that "much can be done about disability." Billions of dollars are spent researching prevention and cure of undesirable medical conditions. Besides, disability is clearly and intensely related to class, race, gender, sexual orientation, degree of fatness, age, and other factors that are targets of oppression. These factors greatly influence who is more likely to get sick or injured in the first place; who gets better or worse medical care; who is more likely to be the victim of medical experimentation; whose diseases receive research money; and so on. So, to do something about these oppressions is to do something about disability.

But beyond that, who develops a medical condition is also a matter of chance — a fact disputed by those who believe that god punishes the wicked or that, invariably, we create our own reality. One child in a family is born with Down's Syndrome or with Sickle Cell; the rest are not. One teenager on a high school trip dives into the shallow part of the lake and becomes paralyzed. One middle-aged friend develops Multiple Sclerosis. This element of chance has helped to obscure the political nature of *all* disability.

A further source of mystification is that, with most oppressions other than disability, most people see that the only problem is the oppression itself. The problem with being Jewish is not Jewishness, it is anti-Semitism. Being a woman in the world would not be a problem apart from sexism. But a severe medical condition appears to be in itself very bad luck. In the world as it is right now, any normally sensitive person realizes that the event of severe disability is catastrophic for the person involved and for those who love and must care for that person.

But the situation of disabled people can be vastly improved even when their medical conditions can't be. Often in fact nothing more can — or should — be done than has been done to cure a particular person's medical condition. That is the point when the status quo discourages our asking several large questions, specifically: How has the quality of life become worse? What systems and what individuals profit from this poor quality? What can be changed, and how? To raise these questions, answer them and take action attacks the core of a system geared to mega-profits.

Maybe this potential threat to exploitative economics explains why William F. Buckley spent an entire editorial reiterating the clearly apparent fact that crossing the ocean in a computer-equipped sailboat would not make a blind sailor see (and was therefore by implication an absurd endeavor). Buckley didn't concede that a blind person with a cane is better off than one without any tool for mobility; that a blind person with a computer that generates print into voice is better off than one who has no way to read; nor the implications of this train of thought.

The system depends on our remaining with the view that nothing can be done about disability and that people who can't be cured must adjust to a life that is less free, less secure, less dignified, and less fun than an able-bodied life. This tradition has caused many disability rights activists to become angry at the concept of "cure" and at the same time at the concept of "accepting one's disability." Instead, they want solutions that enable life with medical conditions to be as good as life without these conditions — a radical concept on which an economy based on exploitation can't survive.

MOVING ON FROM HERE

For people with medical conditions to begin to see disability as a human-made construct, a manipulation on the part of an economic system, is a basis for new hope.

But it's a profound threat, too, because the fitting response to that understanding is a deep, strong anger — not at God, the cosmos or self, but at our physical and social environment and the people who perpetuate that environment through their attitudes and their policies.

And people who are disabled often cannot afford to express anger. Their lack of power makes them dependent moment-to-moment for their most basic needs: getting food from the refrigerator into their mouths, going to the bathroom, having access to essential information that is at any given moment being written or spoken.

To express anger toward someone who in ten minutes is going to be needed to help you use the bathroom is dangerous, emotionally and physically.

The stakes are, in fact, very high. A person repeatedly prevented from expressing anger learns over time to stop even feeling the anger — or any strong emotion. At some point, the views which perpetuate the oppressive situation take up firm residence in the oppressed person's own head in order to complete the task.

To fight against ableism involves very real dangers to people with disabilities. And for both disabled and non-disabled people it requires a new and very different way of seeing, thinking, feeling, and talking about disability, acting in new ways, and making new structures.

For non-disabled people, a political view of disability can begin to remove a burden of guilt or helpless sadness as they confront disabled people. The panic, revulsion, nervousness or embarrassment that many non-disabled people feel when confronting disability are not character flaws — they are socialized feelings nurtured by systems that would stand to lose if people with medical conditions were considered as valuable as anyone else.

It is to our advantage to build an environment where the economic structures, the physical structures, the technology, the vocabulary for giving, receiving and negotiating major help create an environment where people with medical conditions can be happy and powerful, and no one needs to be afraid of illness, accident or aging.

The implications for Radical Psychiatry are deep and wide. First, Radical Psychiatry theory has provided an impetus for tracking down political roots of disability oppression: the very simple formulation that almost all bad feelings result from internalized or external oppression motivates a search from confused pain to clear reasons.

Disability issues permeate the work of healing souls:

- A person in group is doing body work. How does a psychiatrist heal the Pig damage not only of how bodies are “supposed to” look, but how bodies are “supposed to” function?
- A woman in group is discussing her upcoming amniocentesis, with the plan of keeping a medically “normal” fetus and aborting a medically different one. How is the group's response to this similar to or different from a plan to keep a male fetus and abort a female one?
- A household comes for a Mediation, and one of the members has a chronic debilitating illness. What are the things the Mediator needs to listen for and the questions s/he needs to ask?

The concepts and tools Radical Psychiatry already uses are well-suited to fight disability oppression. For instance, facing disability issues nationally and interpersonally calls for the most focused attention to distinctions between real scarcity and perceived or manipulated scarcity. Disability issues call for great amount of permission and protection as people express feelings and identify Pigs; they often call for a wider and deeper analysis of the Rescue Triangle than is commonly conceived; and they provide an opportunity for highly creative and meaningful approaches to cooperation.