

Judy Snow: Stalking the Bureaucracy
in a Wheelchair

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When Judy Snow, a severely disabled quadriplegic from birth, wheeled into her press conference at York University in Downsview, Ontario on May 30th, she pounced on the fear which haunts the bureaucrats' dreams. She talked of precedent. The provincial government had just set a precedent by granting her a subsidy to help pay an attendant. In a tone typical of her enmity with government, she seized on her victory, urging the estimated 2,000 disabled in Ontario to press forward with their demands.

Although she claims you "lose your soul if you hang around government types too long; it becomes a form of prostitution", Judy Snow stalked the social services ten long years before her breakthrough. And she does not appear to have lost her soul.

② ~~To the contrary. The poise, the feistiness and a~~
~~that everyone~~
~~almost make me forget~~ Judy Snow's physical prowess equals one functioning

thumb (which she uses to steer her electric wheelchair). And everything

works from the neck up. Formidably!

① Judy Snow is a 31 year old woman with a
her lively round face with one unnatural dent in the forehead (the
result of traction from an operation which implanted a titanium rod in her
back to make it rigid). ~~Her short cropped hair~~ is capped with her trademark, a jaunty hat. "I like
hats, especially if they're bizarre; besides, it gives people something else
to ask other than why I'm in a wheelchair". Sometimes she ~~wears~~ sports a hat
of special significance, a weathered cowboy style in leather, which passes
as a sort of honor amongst a group of people who have made commitments and
sacrifices to help other people out". ~~She names~~ Charlie Tann, an ex prisoner &

good friend
who crusades against certain abuses of the ~~criminal~~ justice system gave Judy the
hat in a small personal ceremony at a friend's home

③ As Judy Snow sits there with the cool of a carefully conditioned
fighter, it is hard to conjure up the gruelling routines inescapable in her
daily life. Every simple task ~~is~~ a monumental undertaking. A life of total physical
dependence, of Hoyer lifts and bedpans, of "inaccessible places and insensitive
people", a life where the mundane detail becomes a problem demanding a
skillful solution.

Peter Clutterbuck, a friend and associate from the Canadian Mental Health Association who scaled the bureaucracy wall with Judy, feels the strains have taken a toll. "Her ten year struggle has made her hard in some ways, even difficult to get along with. She's had a hard life, learned not to trust many people. If you're going to be her friend, you're going to be tested ". "But", Clutterbuck adds, "she's different from most handicapped people. They are mostly submissive, mostly resigned to poor treatment. They don't know they have any rights".

After a decade of buffeting the rapacious tide of the welfare industry, Judy won a promise from Keith Norton, the Ontario Minister of Community and Social Services (COMSOC) for money. But not much of it. A letter signed by the Minister which arrived by courier the night before the press conference (originally called to denounce the government for non-support) promised \$1,250 a month for 5 months retroactive from April to September..

According to Clutterbuck, "Judy would not have gotten even what little she got without support". John Anderson, the Assistant Deputy Minister in COMSOC's Adult Services Division seems to agree. He also contends poor governmental understanding of the abilities of the handicapped account for bureaucratic hesitation to support individuals outside institutions. These "individuals have to prove they have a capability we might not have thought them capable of". Besides, in Judy's case, "she has lots of support and voluntary backup. I understand that she has faculty and student groups behind her".

In explaining why Judy Snow's is the only case of one-to-one care temporarily subsidised by his department, Anderson says "Judy is an extreme case, very keenly alert, has accomplished a Masters degree and can coordinate her own care".

Nonetheless, he feels tremendous advances have been made in the last 5 years towards deinstitutionalising the handicapped. COMSOC now supports about 178 people in smaller living units such as group homes, and he wants to see Judy in a new housing project for the handicapped at York come Fall.

Judy ~~now~~, however, complains the picture is not so rosy, that the process of being accepted for any project or any support is long and tedious. The struggle which wrenched a few pennies for her from the tight-fisted machine revealed a special irony which governs the life of Judy Snow and many others like her. She maintains her battle to survive ~~has~~ not been with the infirmities of her body but with the castaway ideology of public and private social services. She is intimate with the meaning of being "up against the system".

A small circle of supporters have been up against that system with her. Peter Dill, a worker with the National Institute on Mental Retardation and a founding member of Judy's main support group, the Joshua Committee (breaking down walls), helped comb the bureaucratic echelons. He thinks she has been "deeply wounded by the society but her life drive is very strong and determined, not only for herself but for others in similar situations".

The wounds come from ^{enough} experience with denials, rebuffs and buckpassing to fill 5 pages of a personal statement with names, dates and places of her ~~unsuccessful~~ attempts to win financial support. After wading through the welfare maze from ministerial top to functionary bottom, from Homemakers to the Ontario Federation of the Cerebral Palsied to the Metro Toronto Department of the Elderly and Disabled to name a few, after winning little more than words of concern and fruitless promises, she wrote with brittle anger: "I am at a point where there are no more regular channels...In desperation and frustration, I have finally decided it is time to let people know how unjust the system is, and how willing some people are to let me die...I refuse to die because a wealthy system can't work out some administrative

difficulties".

In response, John Anderson feels that "depending on the degree of power individuals dealing with Judy had to provide for her needs, some people might have given some evidence (for Judy's charges). But I don't think there is a callousness in the workers who dealt with her". He accounts for her series of refusals by explaining her personal income was a "barrier to assistance in terms of the legislation". At the same time, he agrees that her income could never have paid for attendant care.

Judy's criticism of the government is unrelenting. "The state doesn't need me. They want to throwaway invisible citizens. I'm disabled but they treat me as if I'm sick. They build hospitals for me but they won't provide me with money to live outside a hospital. Their real interest is in deathmaking, not ~~is~~ lifegiving".

In the 10 years she has lived away from her family home, she has rarely had enough money to live without fear. Vocational Rehabilitation paid the bills for college, but once under the jurisdiction of Family Benefits her disability allowance shrunk to \$250 a month in the inflation ridden days of 1976-77. There was no money to pay for attendant care. (Judy needs 4-5 hours of physical care a day.)

Consequently she was forced to spend three and a half years in hospitals for the chronically ill. Institutionalisation of the handicapped is "more or less the tradition of care in this country", says John Anderson. He adds, "Maybe it is not the right one but I don't think on the basis of what we are doing today we have to justify what we did 9 or 10 years ago".

Four years ago , Judy claims to have been pressured out of Oak Ridge Nursing Home because she needed too much care. Later in Weston's West Park Hospital she roomed with a woman of 101 years. Her previous

roommate had been 86.

She speaks sardonically of those hospitals, or "prisons for the criminally infirm", as she calls them. "People die needlessly all the time in places like this, they die because of lack of care. Usually their families are coopted not to protest. I would have been dead if I hadn't fought back. These institutions want to keep people in bed with someone else having control over every aspect of your life. I was punished for being aggressive. Sometimes they would bring in my food tray and leave it by the bed, but no one came to feed me. This happened often enough to deprive me of certain nutritutional needs".

This treatment didn't discourage her will to upset hospital routine. A survivor, Judy Snow broke the rules, fleeing sick bay everyday for her job as Coordinator of the Centre for Special Services for Handicapped Students at York University. With a Masters of Arts in Clinical and Counselling Psychology, she also teaches part time in Special Education. Not satisfied with the scope of her career, she will be entering Osgoode Hall Law School in the Fall.

She laments the fact some people imagine the handicapped "lack the desire and ability to accomplish anything. People don't imagine I have the normal desires of a 30 year old woman for career, friends and lovers". Her accounts of how untrue this is switches from the personal to the professional.

"I hate to think I could be a 30 year old blasé, bored, middle class housewife. I'd like to be married but I'd value a husband more than most women. About 6 years ago I had a serious relationship with a pre-med student (not handicapped). We made great friends and were considering marriage but it didn't work out".

Professionally, she is sensitive to the myths that surround the sexuality of the handicapped, and her office handles many requests for information from disabled youths. "Until recently, people normally assumed that handicapped people didn't want or weren't able to have sex. Neither is true. In a rare case where a person can't have ^(a sex life) in the normal way, they can in other ways; they can enjoy sexual satisfaction".

As for friends, Judy Snow seems endowed. Various friends and associates helped her escape an institutionalised life. By last October, she put hospitals behind her as she moved into her own apartment in student quarters at York. Settled in her own place, Judy put her frighteningly able managerial skills and her popularity to work, organising a contingent of volunteers to supplement^{ment} paid part time attendants.

Sandy Gray is typical. A full time mental health worker, Sandy began on a voluntary basis after 5:00 acting as "coordinator-attendant" (attending to a portion of Judy's physical needs and coordinating the shifts of other volunteers). When Judy insisted on paying, Sandy used her wages to buy a stereo for Judy. With apparent admiration, she comments that Judy is "highly intelligent, resourceful, fun to be with - a great lady".

Cydnee Hosker, a student of Visual Arts and Special Education, has taken over Sandy's post. She has also adopted her sentiment. While she emphasizes that helping Judy is her full time summer job, and a "great experience for my studies in Special Education", sounds of respect and friendship overshadow her talk of the hard work.

Despite loyal attendants and a stunningly active and varied life, Judy Snow's battle is far from over. The COMSOC grant won't go very far, not even far enough to arouse more than measured words of congratulations for the government. Judy points out the limited funding came only after

a colossal ^disproportionate struggle. (Her aim is a guaranteed \$15,000 a year. It costs \$20-\$30,000 to keep someone hospitalised for the same period). The funding came only after COMSOC had every reason to fear a ~~major~~ ^{public} protest by people with wheelchairs, crutches and seeing eye dogs. ~~impartial~~ ^{parties}.

In the process of fighting, of organising and ^{of} threatening, Judy and the Joshua Committee became a symbol for many of the disgruntled handicapped in Ontario. When a few hundred of her confrères assembled in March at York for a conference on the rights of the handicapped, her fight became a beacon in their common struggle to wrench concessions in financial support, employment, education, transportation and public facilities from the government.

Judy ^{believes a common bond exists amongst} ~~is fast to point up the common cause of~~ all categories of people treated as marginals. She talks animatedly about the "marginal mentality", the self put down which often characterises groups who suffer the fate of worn out shoes. "They have little sense of their own abilities. Disabled people have to be educated to their strengths. We're labelled disabled, we get poor, segregated education and many of us know nothing. But this is true of any devalued population which is kept separate and ignorant".

To counter at least some of the obstacles which block the handicapped, Judy helped form and is president of R.A.M.P. Opportunities Inc. (Reliable, Able, Mobile People) which wants to innovate devices for the physically handicapped. She's also a mover in the bid to introduce a rehabilitation programme at York to train ^{as a} counsellors. Her responsibilities, ambitions and schedule ~~are~~ ^{are} for the kind of indefatigable energy which swathes the long distance runner.

But she is far from being able to run, a fact which has governed her life. Born to an Ontario middle management family, she defied the odds in education for the handicapped. Her family moved three times to find school superintendents who were willing to admit her to regular classes (their power in Ontario

education is roughly equal to that of the Pope in the Church).

While her adult years have been marked by the stereotypes, prejudices and mechanical coldness which a social system based on profit naturally assigns to ~~those~~ those lacking the opportunity to be very productive, her childhood was no more palatable. "Many people thought I didn't want to be involved, or they consciously tried to exclude me. I was never invited to kids' parties and even the Girl Guides told me I didn't really want to join".

But Judy has insisted upon being a joiner, whether joining in a Saturday afternoon Go game in a friend's garden or being wheeled along the boardwalk at Toronto's Beaches area. She knows even the achievement of small but normal pleasures help make her a role model. As Peter Clutterbuck says, "she's an example not only for the handicapped but also for any people who have been abused by the system".

Her life is made of the stuff which produces either uncompromising scrappers or hopelessly compromised quitters. Only under duress will she admit a desire to be physically able. Routinely, rather than bemoan her handicap, she almost makes it sound like a strength. "People I draw around me are honest; perhaps I wouldn't have had that opportunity if I weren't disabled. I think I attract people who are struggling for a better world".

With that impetus at the centre of her own life, it will be no surprise if she and the people around her haunt many more bureaucratic dreams.