

TITLE:
THE JOSHUA COMMITTEE
AN ADVOCACY MODEL

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Judy Snow

INTRODUCTION

This article is in two parts and written from the perspective of two women - one is in a wheelchair, one stands erect; one has to have full attendant care for all her physical needs, one can care for herself. Both are dependent on others for spiritual, intellectual and moral support. Both are committed advocates for the rights of disabled persons. Both are seen as strong and independent women.

Both feel the current situation for the handicapped is unjust. Both are fully functioning productive citizens - although because one is labelled "disabled" her choices in life until now have been severely limited.

The following story, from the perspective of each woman, tells how by combining the efforts of concerned individuals small battles can be fought and won. Though small, these battles show others that they too have a right to live in this society as fully functioning persons with the same rights afforded to everyone.

Part I -- by Marsha Forest

Strangely enough, when I went to visit Judy Snow for the first time at her home, I discovered that she was living in a chronic care hospital - a hospital designed to care for the sick and aged -- and a hospital that was traumatized by the spunky vitality of a woman who went to work every day like the "normal" person she is. Unfortunately, this hospital was designed to take care of the sick and not to send a healthy person out into the world to work every day. Judy's "normalcy" challenged and irritated the purpose of the hospital because she refused to be sick.

Judy's job was Director of the Centre for Handicapped Students at York University which she herself founded in 1977. Against all odds she fought the hospital mentality and went to work daily, but she was getting psychologically worn out and when I met her she was frantic to get out of this stifling environment.

"How can you live here?" I asked in amazement. "Doesn't it drive you crazy? You who are so energetic and competent and normal. How can you stand this? It's awful!" My husband, Jack, also a friend of Judy's, echoed my sentiments.

I didn't realize until a year later, at the celebration of Judy's first year out of the hospital, that Jack and I had played any role in influencing Judy to leave. But we did. Simply by responding to her plight, by saying how we'd feel all cooped up, we legitimized feelings she knew were right. But most people around her -- the professionals, her nurses, social workers, doctors, etc. -- kept telling her to adjust. Telling her she was better off where she was and that it would be impossible for her to leave. When she got depressed or upset she was called "manipulative, bossy" etc.

After ten years of a battle with the social service bureaucracy Judy, as I also found out later, was seriously contemplating suicide. To me this response was normal and logical. How would any of us able-bodied persons feel, locked away in a hospital room without being sick?

Judy told me later that she began to think "I'm not crazy - others agree - I'm going to leave." She left the hospital and so ensued a one-year battle with the social service bureaucracy of Ontario and Metro Toronto for the simple right of Judy Snow to live as a human being in the home and community of her choice.

Judy Snow is a symbol. She is also an individual. The fight was for both Judy the person and Judy the symbol of so many others unfairly institutionalized. In the week of June 1, 1981, Judy Snow moved - not back to the hospital, but to a lovely one-bedroom downtown Toronto apartment. Her attendant-co-ordinator has a bachelor apartment in the same building. It is a far cry from the situation at West Park Chronic Care Hospital.

For Judy Snow and her family the struggle has been for a lifetime. For me, only the three years since I met Judy Snow.

What was Judy's demand? Simply the right to choose where and how she would live. This simple choice threw the entire social service system into a panic.

How did we win this small battle for such a human right? I say "we" for the way this battle was fought and won was with the co-operative effort of a united group. In fighting for Judy Snow we were each fighting for our own

dignity and self-respect. For truly an injury to one is an injury to all.

Formation of the Joshua Committee

Judy emotionally and physically collapsed on March 6, 1980. It was miraculous she had not collapsed sooner. After all, she was not just the director of the Centre for Handicapped Students at York University, but the co-ordinator of her own attendant care system. She worked full-time; helped so many others and finally very quietly said, "I can't go on - I can't ask anyone, anymore, to do anything else for me."

That weekend the "Joshua Committee" was born. As Judy lay in a friend's house confronted by many caring people, among them a loving yellow labrador named Shaunee, a group was formed.

I should point out here that Judy can take care of no physical needs herself including feeding, bathroom, scratching, etc. She needs virtually full-time attendant care which she had to organize and co-ordinate by herself. The pressure was incredible because if someone "forgot" or couldn't make it, Judy would be left sitting in her wheelchair without eating, going to the bathroom, etc. A mistake could be fatal.

Alone, none of Judy's friends could deal with the enormity of the crisis - yet we had all expected Judy to do it. Now we began to see how hard she had to work simply to live.

Judy herself dubbed this support group The Joshua Committee because we were going to break down wall. Each member had both general and specific

tasks: Peter K., budget; Peter D., spiritual; Cydnee H., health and attendant care; Marsha F., social and professional; Sandi, rest and relaxation; Jenny C., campus relations. We were all friends. We had many meetings at first. We never gave up or gave in, although we got more angry and tired. We were constantly amazed that Judy had indeed survived so long.

We won our demands in the long run because we broke down the bureaucratic barricade by a personal appeal.

After endless meetings, we were all getting worn out. Our demand: that the government provide money for attendant care services for Judy so she could keep her own apartment. Peter K., our budget expert, had clearly shown cost-wise that the government would save. But the issue was far deeper than money for we were challenging the hospital system itself, and the entrenched attitude that "these people" are better off in hospitals and institutions.

We decided, before storming the bastille, to invite the policy makers to come and see for themselves how Judy's system was working in actual practice. We invited the "faceless bureaucrats" to meet Judy personally, face to face on her own territory -- in her own apartment and with her volunteer and non-volunteer attendants. Our system was built on a personal base and this is what we wanted our adversaries to see. The busy bureaucrats who came that day left with a different point of view. Each of them or any member of their family could become disabled. We faced them with their own vulnerability. Would they choose a place of their own or a hospital room?

We won! An order in council was put forth for Judy Snow "as an individual". They told us not to say it was a precedent or a policy. We called a press conference and said it indeed was a precedent (but not a policy). Judy had won the money needed for attendant care. Others could now do the same.

By example, Judy had shown other disabled adults that there were choices. She never said all handicapped people should live in their own apartments. She and the Joshua Committee said that handicapped people, like non-handicapped people, should have the option to live in apartments, houses, communes etc. The issue was and is CHOICE.

We learned that no one can fight and stand alone, and that advocacy groups like the Joshua Committee, volunteer in nature, can assist handicapped persons fight the daily battles that often wear them out.

It was the little things that were driving Judy crazy. She could handle the big jobs like working for a living, but she couldn't handle the picayune details - the constant phone calls, the daily annoyances, the broken wheelchair, the need for secretarial assistance -- all solvable problems, but not easily dealt with by one human being.

Today Judy Snow and the Joshua Committee meet only once or at most twice a month. We even recruit temporary Joshuas to help. For example, Jack P., who is designing a new system to make going to the bathroom an easier process for Judy.

We can start now to deal with new issues. For example, better medical care, exercise, culture, transportation.

The Joshua Committee members have a wide variety of interests and opinions, but they keep their aim in sight: the life of one human being, Judy Snow. Through this one issue, however, we reached and touched many others.

The walls haven't all come tumbling down, but we made a dent. Other Joshua Committees are popping up in Toronto. At least three others that we personally know of are in existence. That is our real success and if we can assist anyone in using this advocacy concept, please call or write.

Members of the Joshua Committee and Judy herself are involved in many other issues. Some have accused us of being so involved with Judy that we ignore social policy, etc. In our experience, we have found that working for one individual and wider social policy changes are not mutually exclusive but are indeed complementary. We have found that those interested in the life of an individual are also those most interested in social change on a wider scale.

Part II - by Judy Snow

In our society people labelled handicapped are usually exposed to severe devaluation. Often they are institutionalized, or otherwise abandoned to whoever is willing to provide them with some standard of care. Their own capacity to contribute to society is rarely recognized, and in fact, the mere process of keeping them out of regular society is enough to make their contribution impossible.

Where the individual has not been abandoned, we have ample evidence that this person has a unique competence, and a definite role to play as a fellow citizen. The challenge to society is to meet the unusual needs of the handicapped person in such a way as to provide that person with full access to the "real world".

I have used a wheelchair to get about for the entire thirty-one years of my life. I need an attendant to meet all of my physical needs. While I lived with my family as a child, I participated in all of the usual activities of children and received by grade 13 diploma at the typical age of eighteen from a typical high school. As a young adult, with the help of attendants paid through a subsidy, I obtained by Master's Degree from a typical university at the age of twenty-six. I fully contributed to university life in every respect. Then inexplicably when I became a mature adult - assistance for attendant care evaporated. In fact, no assistance for attendant care was available to me as a working adult, and I spent the next four years in an institution. This experience was nearly fatal, and I finally left this brutalizing environment in a state of physical and emotional exhaustion. I left desolate at having no resources for attendant care other than those I

could pay for myself. I knew I would die if I stayed in the institution any longer.

In time, a group of concerned friends and citizens who cared about my well-being formed the Joshua Committee. The mandate of this group of seven people including myself, was to assist me in getting a functioning attendant care system, and to otherwise make it possible for me to be a functioning citizen once again. After a few months of strong advocacy on their part, an Order in Council from the Cabinet of the Ontario government mandated a unique attendant care system designed by the Joshua Committee (and me) to meet my needs.

I now have a paid co-ordinator for my attendant care. This person hires, trains, schedules (and occasionally fires) a group of paid and volunteer attendants. The attendant care schedule includes five periods of care each day. These periods are a two hour morning session, a one and one half hour lunch time, a one and a half hour supper time, a three-quarter hour bed-time and an all-night sleepover period. These time slots are each filled by an attendant, and are flexible as to time and place. In other words, I can now decide when I will get up, when and where I will have lunch or supper, and what time I will go to bed. The attendants may also travel with me so that if I am working in another city, or if I decide to move my place of residence, the system is flexible enough to accommodate these changes. The co-ordinator provides some of the attendant care, and equally important, hires and schedules other attendants who are able to keep up with my varied life style and needs. Activities during the scheduled time slots include washing, dressing, feeding, toileting, paperwork, housekeeping and other necessary

activities. The co-ordinator and I work closely together to keep in touch and to work out any problems.

As the government of Ontario was unable to contract directly with an individual, Frontier College (a unique adult education institution) has provided the necessary institutional capacity to hold the contracts. Each month the government of Ontario provides Frontier College with \$1,500 on my behalf. Frontier takes a small amount for administrative fees, and pays my co-ordinator \$667.00 per month. The co-ordinator in turn can use the remaining money to hire attendants at approximately \$4.00/hour to fill out the schedule. Additionally, several attendants have volunteered their time and efforts, and all of the people who sleep over are volunteers. Consequently, the cost of my attendant care is less than one half of what it would be if I had remained in the institution. Furthermore, my personal system has a much higher capacity to respond to my unusual needs.

Many other aspects of the system are unique besides its capacity to meet my individual needs. This system is the only one in Canada that does not demand that the person who needs the attendant care move to the building where the attendants are working. Usually the person must move to the hospital, residence, etc. and leave his or her home. In our system, the attendants come to my home, or where I am at that time. Thus I have, in fact, a real home in a typical apartment building.

Furthermore, the co-ordinator works with and is responsible to me, so that as my needs change, the system changes its response appropriately. Under other systems my needs would only be met to the extent that they matched what the system was willing to provide. Most handicapped people have little

or no choice about what happens in their life. My choices are now respected and met. Finally, this system is uniquely inexpensive as it only attempts to meet my real needs, and not other needs such as shelter, administration or other needs created by building an institution.

The attendant care system has been in place since May 1980. During that time I have been a part-time lecturer at York University, have worked closely with the Toronto Citizen Advocacy Steering Committee and with the Advocacy Programme of the Canadian Association for the Mentally Retarded. This work has taken me to Montpelier, Vermont; Windsor, Ontario; Owen Sound, Ontario; Kamloops, B.C.; Winnipeg, Manitoba; Syracuse, New York; and Atlanta, Georgia. I am considered by the "experts" to be severely handicapped. To some I am a quadriplegic, but to others I am an active citizen, and Judy. The Joshua Committee has proved that the second point of view is not simply a dream but an actual possibility for many other devalued persons and a current reality for me.

We urge people to contact us with their comments, criticisms or suggestions. You can write to:

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