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## Living at home\*

Judith Snow

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Four years ago I moved into my own apartment at York University with my own cadre of personal attendants. This step was both a major change in my own life and a major political victory for Canadian citizens labelled handicapped. I would like to outline the story in this paper so that others can use my accomplishment as a model if they so desire.

I was born in October 1949 to an ordinary couple in the city of Oshawa. These people had had two ordinary children before my birth and would have another ordinary child when I was two. Only two things make my family particularly remarkable: one is that I was born with an unusually and severely limited use of my own limbs. The second, more significant difference about my family is that my parents believed in my potential to be useful to myself and to my community. They believed I should have an ordinary chance at fulfilling my potential.

Their belief in my potential as a human being marked my life and my family's career from that early moment. Society did not believe in the potential of citizens with severe handicaps. Therefore, my parents were quickly initiated into the red tape, inefficiency, short sightedness and occasional maliciousness of the service structure that is supposed to meet the needs of people like myself. We soon grew to know that we could expect little help and much bad advice.

My parents realized that I could and needed to contribute to ordinary peer relationships and experiences in my growing years. They know that I needed a good education to open options for me as I approached adulthood. Consequently, we drove many miles, fought with several school superintendents and moved twice so that I could gain opportunities to learn and play with ordinary school-mates. My family also made or purchased my own special devices, and generally put in an extraordinary amount of time, energy and money.

Two years before I was ready for university, my parents took on the

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Vocational Rehabilitation Branch of the Ontario Ministry of Community and Social Services. We won a grant to hire an attendant who would provide for my physical needs at university. Two months before my nineteenth birthday, I became an independently living adult in student residence at York University. Within the year I recognized that there would be no support for the cost of my attendant care when I graduated from university. I recognized that institutional life was awaiting me when I completed my student days. I and other handicapped people banded together at that point to encourage the development of community-based services for people with physical handicaps. Along with others, I worked on the Kellerman House Committee and the Clarendon Foundation. Partly due to my efforts new services were funded, but always for people with relatively mild handicaps. Those of us interested in the participation of citizens with severe handicaps were thwarted at every turn.

In April 1976 I completed my Master of Arts program, lost my funding for attendant care and entered a nursing home. For me and my family this represented a defeat of our entire effort to support me as a contributing citizen.

During the following three-and-one-half years, I was forced to move from a nursing home to first one, and then another, chronic care hospital. The stated reason for this destabilizing journey was that the nursing home was unable to provide more than two-and-a-half hours of actual care in the day. I am a person who needs a minimum of five hours a day of attendant care. During these three-and-one-half years, in order to maintain my sanity and my interest in the outside world, I continued to work four days a week at York University. The money I earned was used up in paying for a semi-private room, a private nurse in the mornings and my transportation.

I needed a semi-private room because patients in a ward room often get little sleep as beds are changed during the night, people are turned, medications are administered. If you stay in bed all day, a short night's sleep is of no consequence, but I needed to sleep since I was going to work. I needed my own nurse, since hospital routine would not allow staff to get me up before ten in the morning. In fact, I was breaking the law by working at all, since disabled people who are funded in hospitals are by definition unemployable. The Province of Ontario could have cut the hospital's funding for me because of my employment, but fortunately they turned a blind eye to this. Also, the staff were always overworked and were glad for the hours when I was not around.

Near the end of the three years, two significant events happened. First, I met Marsha Forest and we became fast friends as we worked together on a planning committee for a conference called "Labelled Disabled."

Marsha would invite me to speak to her classes of student teachers who were going into Special Education. Many knew nothing about people with handicaps and Marsha wanted me to tell them the real story.

The second event was that my health began to break down because of the institution, its policies, atmosphere and staff. No matter how hard I worked to explain how I needed to be active, I was always pushing against the life of the institution. After a time they would not let me have a private nurse in the mornings, saying that they could get me up in time for work. However, the staff soon resented my continuous need to be up quickly and early. When I returned each day, it was a battle to get to go to the bathroom, or to get my own supper, as half the staff were on their own break, and the other two had fifteen people in their beds to wash and turn and change in a forty-five minute time period. The pressure on me mounted. The staff tried to get me to stay home, to stay in bed, to give up. Even in my semi-private room, the elderly lady called "nurse, nurse, nurse" in her sleep all night. Under the stress of little sleep and constant hostility, I began to break down physically and emotionally.

In the summer of 1979 I fell ill enough to be moved to a general hospital. Doctors there found that I was suffering from malnutrition and bronchitis. Both of these conditions arose because my schedule conflicted with the hospital schedule. Often staff did not have the time to feed me my supper when I came home from work, or to take me to the bathroom more than twice a day. I was used to getting cold meals that had been sitting around for hours. Malnutrition saps your willpower, and I realized that I had not been fighting back hard enough, and that I would have to fight harder if I wanted to live.

The doctors and social workers at the general hospital looked for another way to get attendant care for me, but even they had to settle for sending me back to the chronic care institution. There were no new services for people needing more than two-and-a-half hours of attendant care. I returned ready to do battle for my life but my extra efforts to get more appropriate service from the staff only made them resent me more. In retaliation, I frequently was assigned a nurse who did not speak English or one that treated me roughly. Marsha supported me in the realization that I was going to lose the battle for my life if I did not get out.

In October 1979 I left the institution to move into the hallway of a friend's apartment at York University.

When I left, I obtained a small grant from the March of Dimes to help subsidize my attendant care. The rest I paid for myself, as well as my own living expenses. I had a letter from the Province of Ontario saying that they were developing a service system of apartments with attendants for the people in the apartments, and that I would be one of the first to move in. I figured I could get by for the six months until this project opened. In

the meantime, Marsha was introducing me to many new people such as Peter Dill, and showing them that I had something to offer as a teacher, a consultant, a friend and more.

In January 1980, the new apartment service informed me that I needed too much attendant care for their service, and that I was not going to be one of their new residents. I was left exhausted financially, emotionally and physically. I toughed it out for about two more months and then collapsed one day in Peter Dill's office.

Peter and Marsha took me to Marsha's house where I stayed for six days. During this time, Marsha called together fourteen people who knew me, and asked them what they were prepared to do in order to get me going again. I did not attend the first meeting, as I was not talking. I have attended all of the others since then. The group decided that I needed my own place to live, money for the attendant care, someone to coordinate the schedule, and ultimately a governmental decision that would permanently fund my special services. Peter found me my own apartment at York within days, and a new volunteer, Sandy Gray, who coordinated my attendants and did some of the attendant care herself for the first five weeks. Later we would hire a full-time coordinator. Another Peter raised a loan from the York University Student Council to pay for several months of attendant care.

Then we all sat down to figure out how we could break through the government's prejudicial policies.

Four years later, I am still living in my own apartment with my own attendant care program which is fully funded by the Province of Ontario. The story of the political breakthrough, and the story of the development of an attendant care program that allows me to work and travel across the country is essentially the story of the Joshua Committee.

Nobody realized it at the time, but Marsha Forest and Peter Dill made history when they formed a support group around me to meet my needs as a person who experiences severe prejudice in Canada. The group started with fourteen people and is now a permanent lifetime commitment for Peter Dill, Marsha Forest, Peter Clutterbuck, Sandy Gray, Krista Chiu, Jack Pearpoint and Judith Snow. As we worked together to create a system that would meet my needs, we were developing a strategy that allows the government, the volunteer community sector and the person who needs services to work together for their mutual advantage.

The Joshua Committee began its work when we made the decision that I as an individual had been dropped through the cracks of the bureaucracy too often. We struggled with the decision that I deserved a support group of my own. As concerned citizens we thought that it might be too selfish to support just one person. However, my life hung in the balance still, and

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we all agreed that I could not afford to be dropped even one more time. We set out to break down the barriers facing me, and that is the reason for the name Joshua Committee as we began to take on the walls of Jericho.

The wall for me is the government's policy against giving money to the individual who needs special services. For years I had been able to document that a private attendant care program was less expensive and more efficient than a group arrangement funded through an agency. For years I and others had known that institutional services kill people. These facts meant nothing to the Province of Ontario as they could not see the logic of funding individuals and not agencies.

Ordinary citizens are very able to understand these facts. Ordinary citizens are not in favour of killing people, nor having their taxes wasted to do it. Marsha Forest organized hundreds of ordinary citizens behind my story to ensure that the Province of Ontario would listen. In addition, we invited Cabinet Ministers and senior civil servants from a number of relevant Ministries to come and see my apartment, to eat lunch with me, and to talk to the people who were hired as my attendants. Not many came to lunch, but those who did were impressed. We gained the ear of the Cabinet, and less than two months after my collapse I had my own private attendant care program.

This crumbling of the wall of Jericho is a history-making event. Since my first contract was signed, approximately 12 other people who needed attendant care have obtained government funding for their own programs. This is the good news. The not-so-good news is that the Province of Ontario still refuses to give money to individuals, and still will not make the provision of individual attendant care into a policy of a Ministry. This means that each individual must find an agency who will accept the government money. In turn the agency gives it back to the individual. This also means that all of the private programs now in existence are written as Orders in Council, directly from the Cabinet level. This is an expensive and time-consuming process for everyone, but the government still cannot see the wisdom of giving money to individuals.

The model of personal support that I have is unique, and we believe worthy of being copied all over the place. I have a group of attendants, two full-time and three part-time, and several volunteers. Three people provide a 24-hour program for me that can go anywhere in the world. The people who advocate for me, help plan and design modifications, and who provide support to my staff are the Joshua Committee. These people are all volunteers, and only Krista Chiu is also an attendant. Frontier College, whose President is Jack Pearpoint, provides the funnel for the money. Then the government provides the money itself which does make my full participation possible. We have shown that the individual, the volunteer

sector, agencies and the government can work effectively together if the volunteer level receives respect and cooperation from the other levels, and if the individual is also respected and listened to.

At the moment I no longer have an attendant care coordinator. We found that an adequate attendant care program, and respect and relationship in the community were the ingredients to spark major personal change for me. Since the beginning of the Joshua Committee I have changed jobs, moved, and changed in many other ways. As I became more active, and particularly as I began to consult across the country and into the United States, no coordinator was able to know where I would be next. Consequently, I now do my own scheduling, payroll, training and the hiring and firing in conjunction with another Joshua member.

Our work together has taught us and others several new things. We have learned that systems of special service can and should be developed around individuals. We have learned that a properly developed service system can compensate for a person's handicap, and literally unhandicap that person. I still can not use my arms and legs, but I can live and work in a normal and contributing manner. We have learned that a community can exercise real responsibility for a member who is handicapped, and do so in a way that enhances that person's own responsibility to themselves and to the community. We have learned that the private individual, the professional and the person with special needs can work together. We also learned that this service can be provided at a significant cost-saving to the taxpayer. My present attendaht care system greatly enhances my life, my work, my friendships and other relationships. The service costs approximately 30% less than what the death-dealing institutional system charges to own me.

I offer my story with the hope that I can communicate a new way of thinking about people with handicaps, and about providing service. We cannot continue to force people with handicaps away from their own homes, families and friends with the excuse that we cannot meet their needs in any other way.

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*Judith Snow is currently working with CACL in the area of family support. She is actively involved in building relationships between people who have been isolated because of a handicap, and ordinary citizens.*

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