

Public Policy that is Hazardous to Women's Health

Privatization of Long Term Care

by Donna D. Haslam

L'auteure partage son expérience de mère d'une fille sérieusement handicapée. Elle explique que les politiques gouvernementales canadiennes qui préconisent la privatisation des soins à long terme sont malsaines pour celles et ceux qui exigent des soins ainsi que pour celles et ceux qui les

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dispensent. Elle ajoute que ce sont généralement les femmes qui sont dispensatrices de soins.

Women are expected to care for children and for people with disabilities. This expectation comes from our partners, parents, children, and friends as well as from professionals and politicians. We expect it of ourselves and many of us are competent caregivers, enjoying the rewards of a relationship where we take on major responsibility while receiving the pleasure of intense emotional attachment. The pleasure can become a nightmare, turning every single day into a painful ordeal when we find ourselves trapped, when we must constantly rely on our own resources and energy in situations that push us to our limits and beyond.

The purpose of this article is to relate my personal experience in caring for Karen, my adult daughter, who is severely disabled due to a chromosomal deletion, and to connect that experience to the political climate of privatization in Canada. What effects has public policy had on my life? What can women expect in future if public services continue to be privatized?

In the mid-80s, privatization became an important issue during the redevelopment of Baker Centre, a government-operated institution in Calgary, Alberta. I was pressured by many people to move Karen into a group home operated by a non-government agency. Those in favor of privatization pointed out that this agency would not be hampered by union rules and would be able to hire part-time help to come in during busier times. This didn't make sense to me. The people who lived at Baker were all severely disabled and it was essential that the people who worked most closely with them were tuned in to their needs. From my perspective, it was important to have full time people who were well paid and felt secure in their

jobs. Saving public money by paying less to staff in private group homes would, in my opinion, lead to decline in quality of care. It would also create lower incomes for people, mostly women, who work as rehabilitation practitioners, aides, office, and cleaning staff. When Baker Centre closed, I chose to have Karen live in one of the nine government-operated group homes that were developed at Scenic Bow Place. Each of these homes has six residents who require 24 hour care. Each resident has her/his own bedroom. Cooking and laundry is done within the homes, vehicles are available for transportation, staff are encouraged to continue their education, and a resource team of various professionals, including a physiotherapist and clinical psychologist, are available for consultation.

Along with staffing, other important aspects of long term care include access to necessary services, continuity of care, and accountability.

With respect to access, it's been my experience that private agencies often refuse to accept people with difficult behaviours or those individuals who require considerable assistance. For example, when Karen was assessed at a private activity centre, my application for admission was rejected because of her disruptive behavior. One of the ways she would vent her anger and frustration was to stuff her clothes in the toilet and wander about bare naked! Government-operated Baker Centre developed a day program to suit her needs and I was involved in planning Parkmont Achievement Centre (PAC) where Karen now takes part in an excellent activity program. I'm concerned about moves toward privatization at PAC. Various strategies are being used to transfer responsibility for this essential service to private agencies and to individuals. For example, an evening program is operated by a charitable organization in the same building as this government-operated day program. Both programs serve the same group of people, those with severe developmental disabilities. While the day program is operated directly by the provincial government, the evening program operates with grants from both the provincial and municipal governments, with donations from various charities, and with considerable volunteer assistance. Even so, staff at the private evening program are paid less than those in the public day program and continuity in the private program is disrupted by frequent staff and administrative turnover.

Where will we turn for services if the only public activity centre in the region is privatized? What will happen to the people who are turned away from private agencies and to those for whom individualized funding is inappropriate? And access to day and evening activity programs is only part of the picture. Residential care is the core service required.

I know from experience how difficult it can be to access

residential services while attempting to provide adequate care at home. When I made the painful decision to find a care facility for Karen it was during the late 60s and my only available option was to have her name put on the waiting list at Alberta School Hospital in Red Deer, Alberta. It took three long, difficult years and a strongly worded letter from our lawyer to Alberta Premier Peter Lougheed before she was admitted to the Junior Pediatric Unit at age seven. The only alternative to coping in my own home was a large institution where my wild and wonderful daughter slept in a huge room with a high ceiling and 50 single cots lined up row on row. It was a

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noisy warehouse for people but I really had no choice. I knew that I was teetering on the edge of emotional exhaustion.

Continuity of care is so very important for people who require considerable assistance in daily living. The nine group homes at Scenic Bow Place are staffed round the clock by public employees who are able to help each other during stressful times because all the homes are in a single location. Caring relationships are well developed among staff and residents and it gives me great comfort to know that when caregivers do leave or become ill, others are there to fill the gap.

Along with staffing, access, and continuity of care, accountability is a fourth aspect of privatization that concerns many of us who are closely connected with people living in long term care. I often hear how fortunate it is that my daughter lives in a Scenic Bow Group Home. Citizen advocates, public guardians, social workers, and review committees all confirm my own perception that these group homes are the best available. I hear that we need more government-operated residential spaces so that people who are being abused and neglected in private care will have available alternatives. Some private agencies and individuals provide good care but, when there is a problem, social workers may struggle to have a vulnerable and dependent person removed from an abusive situation only to find that the next home they enter is no better, maybe even worse. As government-operated facilities are phased out, there will be no choices available. Everyone will have to depend upon private agencies and individuals for long term care.

The strange part of this situation is that private care is being provided with public funds. Various strategies are used by our government to contract out the care of dependent people to foster homes or to group homes

operated by private agencies or individuals. In addition to the concern expressed about lower wages and lack of benefits for non-union workers, privatization creates a buffer between government and citizen. Alberta Family and Social Services is directly responsible for funding and administering Scenic Bow Group Homes. When problems arise, I address my concerns to the Minister, expect an appropriate and respectful response, and persist as long as necessary to bring about change. If my daughter lived in a private home, accountability would be through the particular agency or care provider(s) in addition to the government bureaucracy and the process would be much more complex and confusing.

When I hear the Scenic Bow Group Homes referred to as a luxury, when people imply that residents are receiving more than they deserve, it makes me angry.

When I hear that some people in Michener Center, formerly Alberta School Hospital, are still living in huge warehouse-type buildings, when I see the residents of the government-operated Eric Cormack Centre in Edmonton crowded into four bed wards of an old hospital, and when I hear that many people must continue living in private care that's inadequate, it makes me angry.

When I hear that we can't afford public long term care, that we must move toward private homes and agencies, volunteers and charity, it makes me angry. We need a core of government-operated services which provide essential quality care, including home care. Volunteers, charities and private agencies should operate as optional enhancers with minimal public funding.

In summary, personal experience in accessing long term care services has led me to the conclusion that universal, publicly administered care is essential if we are to have assured access to quality care for our more vulnerable citizens.

This past year has been a time for remembering and for healing the deep wounds caused by eighteen years of personal abuse which began when I made the painful decision to apply for Karen's admission to Alberta School Hospital and ended when she moved into her group home. The cause of my pain was the terrible lack of appropriate public services for Karen. I've also been haunted by the phantoms of motherhood and of community living. It's time to let go of these illusions. Giving birth does not chain me to lifelong responsibility for my beautiful daughter and there is no existing community that can provide the care that Karen requires.

We need to move toward social care and shared responsibility. Women are being pushed to the limits of our endurance. We can no longer be expected to carry excessive burdens of responsibility in caring for loved ones in our homes. Neither can we be expected to place them in large, crowded institutions nor in private homes and agencies operated with public funds. We must have access to public residential care and activity centres that meet the needs of vulnerable people and that are the direct responsibility of provincial governments. Sheila Neysmith pro-

poses a social-care model which would “provide explicit recognition that care of vulnerable persons is not a family responsibility but rather that public services must be made available to people who need them as part of a social security system based on rights of citizenship” (283).

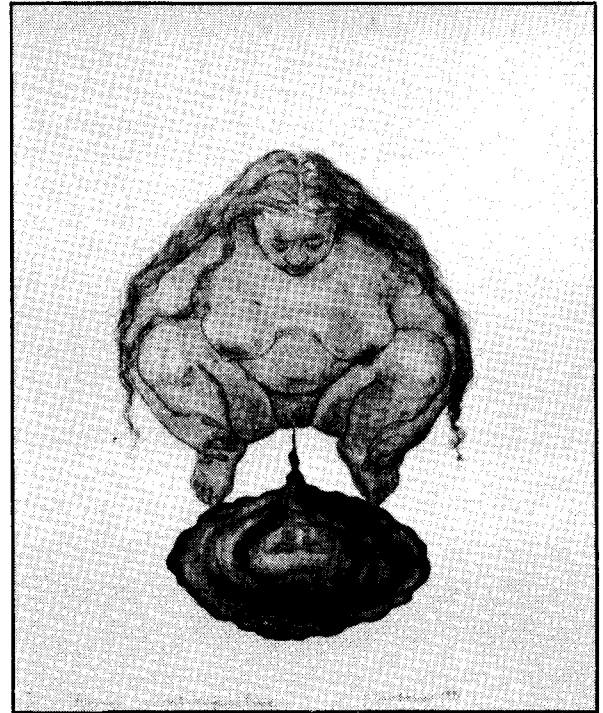
We’ve made a good beginning in the Calgary Region. Government-operated residential facilities and activity centres are essential services and attempts to privatize Scenic Bow Group Homes, Bow Park Court and Parkmont Achievement Centre must be strongly resisted. These group homes, nursing home, and activity centre are located in northwest Calgary, are operated by Alberta Family and Social Services and provide quality care for vulnerable people. It’s essential that we develop similar public services for others in need.

The political climate of privatization in Canada is most unhealthy for people who need long term care and for their care providers who are mostly women. We must recognize that public long term care is not a privilege but a basic right of citizenship. Women need to become full and equal participants in the political process, in policy and planning, if we’re to meet the needs of our loved ones. Men need to value the contribution of care providers (who are mostly women), to tune in to the needs of those who are close to them and to take some initiative in responding to those needs. We must all become involved in caring for and about each other and in creating and sustaining appropriate, public long term care facilities and services.

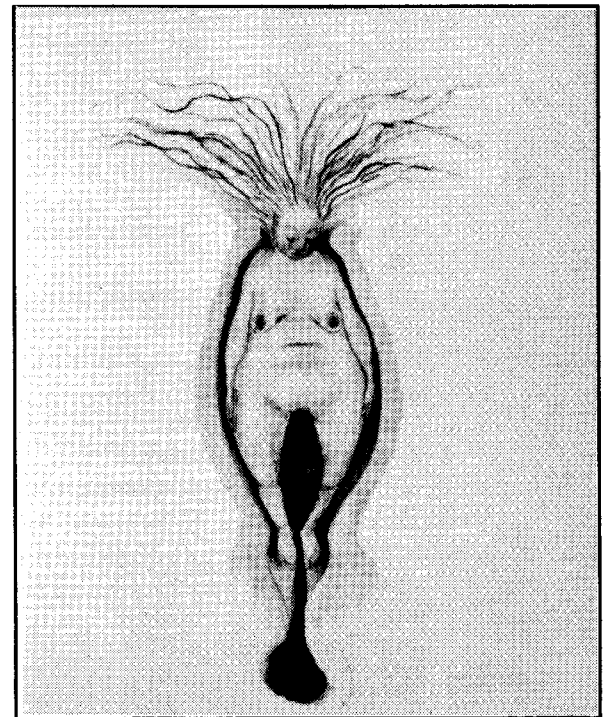
Donna D. Haslam is currently writing a book about her experiences in caring for her adult daughter who is severely disabled. She is working towards a Master’s Degree in Community Health and expects to continue participating in public policy development and in planning long term care facilities and services.

References

Neysmith, S., C. Bains, and P. Evans. *Women’s Caring*. Toronto: McClelland & Stewart, 1993.



Tamara Thiebaux, "Menses Introspective,"
Watercolour, 10x8.5", 1991



Tamara Thiebaux, "Guardienne," Watercolour, 7x6", 1991

"Presenting and displaying nature and natural forces in a light of reverence promotes spiritual, sexual, physical, and emotional health."

Tamara Thiebaux is a self-taught artist whose work reflects the evolution of a survivor, woman, and feminist. Her work challenges destructive attitudes about women.