



Speaking Out Project: Periodic Report #4

Costs, Closures and Confusion: People in Ontario Talk About Health Care

by

Kate Bezanson and Louise Noce
with the assistance of the *Speaking Out* Team

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*This report is dedicated to Olga
(At the request of Olivia's family, this dedication is in her real name)*

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PEOPLE IN ONTARIO TALK ABOUT HEALTH CARE

In its April 1999 Speech from the Throne, the Ontario government claims it is “*determined to continue to provide a universally accessible health care system that provides top quality service to patients, where and when they need it... . We need to preserve a public health care system on which every family in Ontario can truly rely*” [Ontario Management Board Secretariat 1999: 10-11].

Mark, a self-employed person who lives in northern Ontario with his spouse, Jessie, was recently in hospital for a serious health problem. His experience has led him to a different view than that of the government’s about the health care system in Ontario:

The priority should be giving good health care to people when they show up. Period. It should not be trying to eliminate services or discouraging people from using the health care system. The government says that they’re saving money and are trying to make health care more efficient, which is resulting in longer waits for us, fewer services and less inclination to give us services. When we show up, we’re being treated like we’re a nuisance.

Mark belongs to one of 40 Ontario households from across the province with which we have been speaking since January 1997. Many of the 124 household members have raised health care as a serious concern in each of our three interviews with them. From October 1998 through January 1999, we talked with participants specifically about their experiences with health care.

People in the households we interviewed have varied connections with Ontario’s health care system. Almost all reported seeing a doc-

tor periodically, even if they do not have a regular family doctor. Over half talked about relatively recent contact with specialists, such as paediatricians, oncologists or surgeons. About one-third used the services of other health professionals, such as chiropractors, midwives or radiation technologists. Half of households had a member of their family (including parents or grandparents) visit an emergency room or stay overnight in a hospital within the previous two years. About 15 percent have experiences with the long-term care system, some with both home care (such as visiting nurses and homemakers) and residential care (nursing homes and homes for the aged). Among the 40 households, 20 percent have a member who works in some capacity in the health care sector. (See Appendix A.)

Over the last four years, the Ontario government has made major changes to the delivery and structure of health care. Overwhelmingly, household participants told us they are fearful that health care services in the province are deteriorating and diminishing.

Bob is retired and lives with his wife, Rosie, in Toronto. Bob is “*scared of what’s going to happen*” if he has to go to the hospital: “*Am I going to get taken care of or are they going to put me in the hallway somewhere and forget about me?*”

Many participants share Bob’s view that health care is becoming less universal in coverage and less accessible. They are concerned especially about what they see as lack of planning in health care restructuring – hospital beds closed without the necessary community and home-based services being put in place.

Most household participants do not believe that the current government’s reforms are intended to make health care more responsive

to the needs of Ontarians. They tell us that changes such as hospital closures and mergers are not meant to provide quality service: rather, they are cost-cutting measures intended to scale back services.

Julie, a researcher with a disability living in Toronto, explains:

It's economics. We're told that, economically, it's not feasible now to provide services to everybody. If you limit and narrow eligibility, then you're going to be able to keep the budget under control and not have to service as many people.

Like Julie, many of the participants in our study believe that they increasingly have to ask for services that previously they received because they were entitled to them. And health care services themselves are only one piece of the puzzle. Changes in other service areas, like transportation, have added more barriers to getting health care and remaining healthy.

THE UNRAVELLING OF HEALTH CARE IN ONTARIO

For many Ontarians, hospital care is an important symbol of the state of health care. But as one household member in a rural southwestern Ontario town notes: “Health care does not start and end with hospitals.” According to people in our study, the health care system is less able to meet the needs of Ontarians because hospitals have been restructured without ensuring that alternatives – such as long-term residential care or home care services – were in place. A change in one area of health affects the health care system overall.

While changes in the health care sector are not experienced the same way by all house-

holds – members have diverse experiences based on factors such as knowledge of the health care system, geography and income – many of those with whom we have been speaking since 1997 agree that decreasing accessibility and shrinking universality have eroded the quality of health care in Ontario.

Navigating the health care system

For many Ontarians, doctors are the first entry point into the provincial health care system. Most household members say they still receive quality care from doctors. However, almost all remark about the length of time that transpires between scheduling an appointment and actually seeing a physician. Jackie works for a nonprofit agency in a medium-sized southeastern Ontario city where she lives with her mother and her two children. Her daughter has a physical disability. Jackie describes her last visit to her doctor:

It's hard to get an appointment with my GP. He's really busy and that's part of the reason I don't often go. The receptionist says: “Well, we have a cancellation. Come and sit here and we'll see you when we can.” That's what they actually say: “Come and sit here between 10:00 and 12:00 and we'll fit you in.” If you've got a toddler, you just can't do that. The last time I went, I wanted to discuss a possible referral and I wanted to give him some forms for my daughter's disability. After five minutes, he was looking at his watch. He rushed me out. I kept thinking: It's just because he's incredibly busy. It typifies the visits to the doctor lately: It's hard to get in, and once you get in he doesn't have time to talk to you.

Unlike the hospital and long-term care sectors, the Ontario government has not made the restructuring of physician-based care, called

primary care, a priority. In July 1996, a committee was established to evaluate different approaches to the delivery of primary care: Only in 1999 are some pilot projects now being launched. The process has been slow and relatively thoughtful, in contrast with changes to hospitals, which have been quick and imposed with almost no public consultation. Yet the level of service and funding that exists in all areas of health care affects the care that doctors provide and where they can refer their patients. Duncan Sinclair, the Chair of the Health Services Restructuring Commission (HSRC) – the government-appointed commission mandated to restructure hospitals – said that the Commission should have started with primary care instead of cutting hospitals, but because the province was cutting hospital budgets so deeply, he had no choice [Coutts 1997a: A3].

Doctors play a significant role in the kinds of services people are able to access, including specialized treatments. Members of households tell us that their doctors not only diagnose and treat illnesses, but also link patients with support services, such as home care. Many credit quality care to interventions by their physician. Participants who have good relationships with their physicians find that they are better able to navigate the complex services in the health care system.

Sabrina, who works with cognitively disabled adults in Toronto, has glaucoma. She explains the importance of her relationship with her doctor:

I need to get my eyes checked every six months. I asked one of my eye specialists about the change in OHIP [Ontario Health Insurance Plan, Ontario's medicare system] coverage that means you can only get your eyes checked once every two years. He said: "That is not your concern. I will deal with it. The worst thing

that happens is I won't get paid." He basically said that I should just keep coming and not worry about it. So if you have a really good doctor and a good relationship with your doctor, he or she can negotiate you through the system.

In some instances, doctors have helped household members with the costs of prescription drugs. Veronica, who lives in the Greater Toronto Area with her two children, says that her children's doctor provides her with free samples and intervenes on her behalf to help her get services. Like Sabrina, she finds that her doctor is critical in getting the health care that she and her children need:

I'm lucky that I've got the doctor I do. Henry and Sally were both at the doctor's last week and he wanted several tests. He told me to take the tests downstairs to the laboratory. He phoned the lab and suddenly, miraculously, there's an opening. We were in, we were seen and the reports were upstairs within an hour. You must have a good doctor.

Even with a doctor like Veronica's, getting other kinds of specialized care is difficult. Waiting lists for some specialists and specialized treatments are very long. Veronica continues:

My kids don't get the treatment that they need or see specialists when they need to, because they're so high in demand. It's like pulling teeth and it makes me sick. When we finally got an appointment with one specialist, his office called to cancel it. I had booked the afternoon off work to take my daughter Sally. I lost an afternoon's pay and the receptionist says: "Oh dear, the doctor's sick. Sorry. How's December?" I'd been waiting six months! I started to think, what if we get to see this doctor and he says: "If you'd brought her in six months ago, we could do

something about it”? What if it’s too late? What if there’s nothing we can do about it now and we just have to watch?

Factors like geographic location, income, knowledge of the health care system and assertiveness affect the services people can get, and how quickly they can access them. Pam is a consultant who lives with her partner, Bert, and their two children in northern Ontario. She told us that her 80-year-old father who lives alone “*was blind because he had to wait six months for a cataract operation.*” Pam explains:

We’re short of specialists. My skin specialist flies in from southern Ontario in October, November and December without getting paid. People can’t get an appointment with her because she’s booked solid with existing patients. We have a shortage of anaesthesiologists and orthopaedic surgeons. We have lots of optometrists, but we’re terribly short of ophthalmologists.

Anand works in the education sector in Toronto and lives with his spouse, who is employed in the health sector, and their two children. His daughter, Lily, had a sty in her eye – a minor condition that is not usually surgically treated in small children because of the time and services required. His experience illustrates the ease with which knowledge and expertise in health care allowed him to navigate the health care system:

I think with respect to Lily that we have been able to get services that we probably wouldn’t have received without connections. I would say that if it were another parent who had a daughter with the same problem, they probably would never have gotten past the family doctor. Even if I didn’t know an ophthalmologist, I would have pushed anyway. I think we have to look at

this to show that people who are wealthy or have connections get access to services.

In cases where physicians do not negotiate services for household members, participants speak of having to be aggressive in getting access to health care. Those individuals who are articulate and confident can demand services in the form of procedures or tests. Jessie and Mark live and work in northern Ontario. They explain that, in order to get quality care, patients have to be assertive: “*If you’re already intimidated, or already uncomfortable, you are probably not getting good care,*” Jessie says. “*I know that if we weren’t as assertive and aggressive as we are, we would not get the quality of health care that we are getting.*” Frank, who works as a counsellor in Toronto and whose partner, Michael, was recently in hospital for surgery, echoes Jessie’s concerns:

In health care, you need to be the kind of person who pushes. You have to know that you can challenge decisions and get what you actually need from the system. People who speak English as a second language or don’t have the knowledge or the confidence or the skill to be able to negotiate that system have a very different experience with the health care system.

Household members who do not feel comfortable navigating the health care system on their own say they need an advocate. Most acknowledge, however, that friends and family, as advocates, cannot substitute for a well funded and managed health care system. Even those with confidence in their ability to negotiate the system often cannot do so when they themselves are ill and vulnerable. Household participants tell us that doctors can help them to navigate the health care system, but for many the responsibility for ensuring quality and appropriate levels of care falls on their own shoulders.

As Michael's experience reveals, even the best doctor cannot bypass barriers to care resulting from changes in funding and services in the health care system overall:

The technology that needs to exist to provide the quality care that's necessary seems to be in place. But accessing it is difficult. Before I had my surgery, I had to have several MRIs [magnetic resonance imaging services] done. I went at 3:00 in the morning. I would otherwise have had to wait another six or eight months. Something's not right when going to the hospital at 3:00 a.m. is the only option.

The provincial government claims that health care spending is up. Government figures indicate that real per capita spending (i.e., spending adjusted for inflation and population growth) has declined by \$115 per person since 1994-95 (see Table 1), a combined decrease of more than \$1 billion per year.

Hospitals: a symbol of restructured health care

Liz is a retired education worker who lives in Toronto. She recounts her recent experience with her local hospital:

When I last went to my local hospital – which is the hospital I have gone to for years – I had a very bad experience. So when I had my injury, I went to another hospital. I think that it's getting worse in hospitals. Part of it is understaffing and overwork. The government keeps saying that it's going to be better for people in the long run. How is it going to be better when there are fewer beds, fewer staff, less care provided? People who go in for operations have to take everything – even Kleenex – with them. Nothing is supplied any more. It's like you have to take a suitcase on wheels to have an operation. Pretty soon it's going to be like a drive-through: You drive up, they do your operation and they send you home. It doesn't matter

Table 1¹
Ontario Ministry of Health Spending

	current spending (billions)	real spending (\$ 1999) (billions)	population (billions)	real per capita spending (\$1999)	real per capita change from 1994-95 (\$1999)
1994-95	\$17.690	\$18.681	10.963	\$1,704	n/a
1995-96	\$17.643	\$18.331	11.121	\$1,648	- \$56
1996-97	\$17.945	\$18.358	11.272	\$1,629	- \$75
1997-98	\$18.050	\$18.303	11.422	\$1,602	- \$102
1998-99	\$18.366	\$18.366	11.561	\$1,589	- \$115

Source: Calculated by *Speaking Out* Project from Ontario Ministry of Finance Public Accounts (1995, 1996, 1997, 1998a, 1998b) and Ontario Management Board Secretariat Expenditure Estimates (1998).

whether you're well or not, the next day you're out the door.

Liz's recent experience of decreased staffing, inadequate infrastructure and supplies, and rushing people through in an 'assembly line' fashion, has undermined her confidence in Ontario's hospitals.

According to Kate and Carl, who live in Toronto, the speed of restructuring changes not only has affected quality, but also has generated confusion. They are uncertain about where they could access emergency services if they needed them:

Carl: If I had an emergency, if I cut myself or broke my leg, got hit by a car or something, I don't know what kind of service I would get.

Kate: And where? If somebody gets hit by a car, an ambulance can't take them to our local hospital anymore. They don't accept ambulances there. Maybe I am wrong, but that's what I read in the paper.

Carl: Yeah, I think it's a long-term care hospital now, so they don't do emergency stuff.

Kate: And the other hospital is closed down for emergencies.

Carl: No, they'll do them. They'll do emergencies.

Regulatory and policy changes, rather than legislation, have been the main vehicles for altering health care funding and structures. The critical legislative changes occurred in Bill 26, the *Savings and Restructuring Act*. When the *Act* was introduced in 1995, the government faced pronounced criticism for the number of issues the legislation covered, the lack of consultation and legislative discussion permitted,

and – with respect to hospital issues – turning over to the Minister of Health enormous powers, such as the ability to close hospitals. In April 1996, the government appointed the Health Services Restructuring Commission, which had been authorized under the *Act*. As part of the same regulation, the government transferred to the Commission the Minister's power to close hospitals. The unprecedented bestowal of this decision-making authority on an independent appointed body caused many people to believe the government wanted to avoid responsibility for hospital decisions.

Recent changes in hospital organization, funding and location are dramatic. Forty-five hospital sites in Ontario have been closed or will be closing, almost all before the end of 2000, and dozens more have been amalgamated. Thirty-three public hospitals are closing (two already have shut down and 31 more are slated to close). Six psychiatric hospitals and six private hospitals will close their doors. (See Table 2.) Thirty emergency departments are being affected by changes in hospital organization: Six already have closed and two have changed hours or roles; most of the rest will close soon. Whether necessary or not, hospital closures, mergers and funding changes have been poorly planned and implemented from the perspective of household members.

According to the Health Services Restructuring Commission, \$1.1 billion is being cut out of hospital budgets between 1995 and 2003, despite population growth of around 20 percent and eight years of inflation. These cuts represent a 15 percent reduction from 1995 hospital transfer payments of \$7.3 billion. (See Appendix B.)

In response to backlogs and crises, various new funding envelopes were announced for special programs, such as \$25 million for kid-

Table 2
Health Services Restructuring Commission
Directives on Hospital Closures

Region	Hospital Site Closures
Brant County (Brantford)	1 hospital of 3 will close
Brockville	1 hospital of 3 will close
Chatham and Kent County	1 hospital of 3 will close
Essex County (Windsor)	1 hospital of 5 will close
Greater Toronto Area (GTA) not including Toronto	1 hospital of 18 will close
Hamilton	2 hospitals of 7 will close
Kingston and surrounding area	3 hospitals of 6 will close
London and St. Thomas	4 hospitals of 8 will close, 1 new psychiatric hospital built
North Bay	3 hospitals will be replaced by a new one
Ottawa	2 hospitals of 10 will close
Parry Sound	2 hospitals will be replaced by a new one
Pembroke	1 hospital of 2 has closed
Peterborough, Cobourg, Port Hope, Haliburton, Lindsay, Campbellford	4 hospitals of 10 will close
Sarnia and area	1 hospital of 3 will close
St. Catharines and Niagara Region	1 hospital of 11 will close
Sault Ste. Marie	1 hospital to close
Sudbury	2 hospitals of 4 will close
Toronto	11 hospitals of 46 will close
Thunder Bay	3 hospitals of 5 will close

Source: See Appendix B.

ney dialysis in November 1995, or for crises, such as \$225 million to address emergency room overloads in April 1998. Nonetheless, in 1995-96, hospital transfer payments totalled \$7.3 billion compared to a proposed \$6.8 billion in 1998-99, which amounts to a reduction of \$500 million or almost seven percent.

Michael, a former counsellor, recently returned to university to complete a graduate degree. He lives in Toronto with his partner, Frank. After Michael had surgery early in 1998, he told us:

One of the reasons that I decided to have the operation was because the hospital was going

to close. I thought my care providers were going to disappear. I thought now is the right time to do it because they're not going to be there for me and who knows where they'll be. It certainly impacted on me personally. My hospital had become a place I was very familiar and comfortable with. I was concerned about starting a relationship with a new care provider, with a surgeon in particular. I had concerns about the work that it would take to establish the kinds of relationships that I had with the people at my hospital.

In 1997, when we spoke with Teresa, a woman with severe health problems, she explained that she did not know who would provide her

The Story of Hospital Funding in Ontario Since 1995

In early 1995, Ontario's Ministry of Health announced that hospital transfer payments for 1995-96 would be \$7.278 billion. In the new government's November 1995 *Fiscal and Economic Statement*, hospitals were informed that the transfer would be cut by \$365 million in 1996-97, \$435 million in 1997-98 and \$507 million in 1998-99. But at the same time that they experienced funding cuts, hospitals also were promised new funding for specific programs and problem areas. For instance, in late 1995, hospitals were informed that \$25 million would be 'reinvested' in kidney dialysis services; in April 1998, hospitals were promised \$225 million to address the emergency room crises; in March 1999, hospitals were advised of \$105 million more for operating expenses and Magnetic Resonance Imaging services (MRIs).

In order to determine their final budgets, hospitals cannot simply use specific funding announcements to help make up for losses. The \$225 million for emergency rooms is a good example. Although announced in April 1998, no money actually flowed to hospitals until October 1998, when the funding was reannounced. The funding is to be spread over two years and is one-time only. Other promised funds, such as money to operate MRIs, did not cover full costs (some MRIs were approved with only 15 percent of operating expenses covered).

In the 1995-96 fiscal year, hospitals received \$7.248 billion. This represents a reduction – after cutting and re-adding dollars – of \$30 million. The following year, 1996-97, \$7.391 billion flowed to hospitals, but they were not actually getting more money. The government merely ended a traditional one-month holdback of payments. In 1997-98, hospitals received transfers of only \$6.704 billion, down \$574 million from 1995-96 estimates. By late 1997, with many hospitals in crisis, the government announced that a further \$507 million cut, previously announced for 1998-99, would be postponed. Instead, the government proposed a transfer of \$6.805 billion. In its 1999 pre-Budget submission, the Ontario Hospital Association indicated that it required more than \$9 billion in operating funding to keep pace with inflation and population growth. In its proposed 1999-2000 Budget, introduced just before the June 1999 election call, the Ontario government suggested that hospital transfers would increase to \$7.200 billion – still less than funding four years earlier. No details were provided to indicate how the money was to be apportioned, nor how much was one-time funding only.

Hospitals also were promised funding to deal with the results of restructuring imposed by the Health Services Restructuring Commission. Various amounts were announced and later revised. At present, \$1.850 billion has been set aside to cover restructuring costs (basically made up of hospital staff severance payments and hospital renovations to accommodate merging of hospital programs). In 1997-98, \$154 million actually was spent, and \$529 million is slated to be spent in 1998-99.

Hospitals are required to cover a share of restructuring costs out of their own funds. Hospitals pay the full cost of interest expense on debt incurred to fund restructuring, 15 percent of all operating restructuring costs (e.g., severance for laid-off staff) and 30 percent of capital restructuring.

In 1997-98, hospitals reported operating deficits of \$176 million and combined short and long-term debt of \$1.764 billion.

Source: Canadian Imperial Bank of Commerce (1998: 4, 8, 15); Ontario Hospital Association (1999b: 4); (1998: 67, 75); Ontario Management Board Secretariat (1995, 1996, 1997, 1998); Ontario Ministry of Finance (1995, 1998, 1999); Ontario Ministry of Health (1998d, 1999).

care and where she would get it once hospital restructuring took effect. She said:

Right now, I am being affected by all the hospital closures. I go to two main hospitals and those two hospitals are being closed. I'm wondering: Where do my records go? I have to start all over again with all these new doctors. The doctors already know me, the staff knows me. They know what's wrong with me. They know what my treatment is. If I walk into the emergency room, everybody knows me and I know what is going to happen.

Michael and Teresa's uncertainty about their care is not without basis. Teresa explains the effects of restructuring on the availability of doctors within hospitals:

It's hard to see my psychiatrist because he is so busy. He has to be at one hospital in the morning and another in the afternoon. They are amalgamating. Sometimes my appointments get cancelled. It's not fair. I'm losing counselling time. I really need to see him, but I can't because he's stuck in meetings about hospital mergers.

Forced to deal with funding cuts at the same time as they were ordered to close and merge, hospitals administrators have focussed their energy on making decisions about layoffs and negotiating program transfers and mergers with other hospitals, or into challenging Health Services Restructuring Commission decisions, rather than concentrating on health care provision. Under these circumstances, planning has been erratic, at best, and based on financial imperatives rather than consideration of health needs [Richard Ivey School of Business 1997: 7; Coutts 1997c: A3; Skelton 1997: A6].

In addition to hospital closures and mergers, the number of beds in hospitals also has been reduced. From 1995 to 1998, as a result of government cuts to hospital budgets and of Health Services Restructuring Commission decisions, Ontario experienced its largest closure of beds ever – 7,371 beds, an 18.5 percent reduction. (See Table 3.)

By 2003, in the 22 regions that house about nine of every 10 hospital beds in Ontario, there will be 28,749 beds. This constitutes a reduction of 14 percent from 33,295 in 1995-

Table 3
Hospital Beds in Ontario²

	1992	1995	1998
total beds	45,496	39,746	32,375
number change from 3 years earlier	-3,893	-5,750	-7,371
percentage change from 3 years earlier	-9.2	-12.6	-18.5

Source: Ontario Ministry of Health (1998a).

96, despite population growth of nearly 20 percent [Health Services Restructuring Commission 1998b].

Household members have experienced faltering emergency care, low staffing levels in hospitals and reduced patient care. Jenny, who lives in southeastern Ontario with her three children, recently was treated as an outpatient. After her surgery, Jenny had to monitor herself for infection, which she felt ill qualified to do. Jenny told us that she did not think that she was eligible for home care because she receives social assistance. She required full-time care in the period immediately following her surgery and had to rely on a friend to care for her children and assist her with basic mobility and functioning. Jenny says:

For the kind of surgery I had, people used to be kept in the hospital for a couple of days. With the cutbacks, it was an outpatient thing. I was in so much agony. They sent me home. They bandaged up my leg and gave me some Tylenol 3. That was it: Away you go. They didn't give me any clean gauze. I didn't really get any instructions on anything.

Jenny's story shows not only a lack of discharge planning, but also the ways in which pushing patients out of hospitals with inadequate plans for home care may result in poorer health for some. Jenny's assumption that she could not get home care because she gets social assistance speaks to an important concern household members raised – discussed in more detail later – about people feeling less entitled to publicly funded services.

Cheryl and Paul live in a small southwestern Ontario city. Their experiences have led them to the conclusion that, as Cheryl says: “Hospitals are not safe places to be sick anymore.” Paul explains:

When my father had a stroke last year, he went to the hospital and they said: “You have to stay overnight.” There was no place for him to stay, so they kept him in emergency. At some point, about 4:00 in the afternoon, he was still in emergency, and they got a spot for him in the maternity ward that evening, sadly because they boot the moms out so quickly. I don't care where he stays, but it's indicative of the state of the system.

Emergency rooms are where people see the effects of health care cuts most clearly. Most household members point to hospital and bed closures as part of the problem with emergency rooms. Long waiting times in emergency rooms increase anxiety and cause people to question the quality of care provided as well as the provincial government's priorities in health spending.

The inequity of being treated equally: creating the generic hospital

Many hospitals have built reputations on servicing the needs of their respective communities. Their proposed closures or mergers have left some household members wondering how responsive replacement hospitals will be to their needs. While care may be adequate at other institutions, household members point out that some hospitals are more accommodating than others.

In our first round of interviews in 1997, Michael, who used the Wellesley Hospital in Toronto, worried about where people with HIV would go for treatment, as well as the battles that would be fought against the merger with St. Michael's Hospital.³ Over a number of years, the Wellesley Hospital had built a reputation for providing health care services to Toronto's gay and lesbian population. Many in the commu-

nity expressed concern that St. Michael's Hospital, a Catholic hospital, would not provide the necessary outreach to that community.

Michael explained: *"I think that it was poorly thought out. We're taking this incredible model of health care that's been developed for a community and just tearing it apart and it's very disturbing."* In a follow-up interview in 1998, Michael's fears about the attentiveness of replacement hospitals to particular community needs were confirmed when he was admitted to a neighbouring downtown Toronto hospital. He described how he and Frank, his same-sex partner, felt uncomfortable with the attitudes of some of the hospital staff: *"The person at admitting didn't want to put Frank down as my partner; she said there wasn't room on the form. I remember thinking, I don't know if this would be happening at the hospital in my community."*

In the *Speaking Out* report, *Centralizing Power, Decentralizing Blame: What Ontarians Say About Education Reform*, we found that the 'average student,' to whom education reform was directed, did not exist [O'Connell and Valentine 1998]. Similarly, in health, the 'average' or 'generic' hospital cannot meet the needs of a diverse population. The generic hospital is supposed to be able to transcend community ties and cultural specificities. Antonio, a father of three who works as a courier in the Greater Toronto Area, speaks of the effect of having his community hospital closed:

There are definitely barriers to accessing care because there are geographical limitations. With the cuts, hospitals are farther away. It's harder to find personnel who speak your own language.

Participants see their local hospitals as an essential element of what makes health care

accessible. The closing or merging of hospitals increases anxiety. People feel they cannot access services quickly or easily. Leo is a textile worker who lives in Toronto with his wife Maria and their two sons. He says:

What they're doing is closing hospitals and making it harder for communities to get emergency care. They are closing hospitals in point A and they're moving them to point B, and it takes longer to get there. It is very important not to put hospitals far away. There are banks all over. Why are banks so important? They have two or three banks on one corner, why not hospitals?

Household members in northern communities are particularly hard hit. They have to travel greater distances for care and wait even longer in emergency rooms. Barbara voices her concern about restricted access in her northern Ontario community:

It's scary to think what would happen if myself or my kids were sick. Where are we going to go? What are we going to do? How are we going to be treated? Is it going to be here or are you going to have to travel to Toronto? Some people have to go to Toronto and then there is the cost and is there going to be a place for you? Health care is something to be scared about.

Hospital staffing and services

Almost all participants express concern about levels of hospital staffing, the hours hospital staff work and the trend toward deskilling of nursing and support staff. Melanie is a teacher who lives with her daughter and her daughter's partner in Toronto. She likens the working conditions in hospitals to war zones:

This is not wartime. Hospital staff are working like it's a national emergency, the way that Doctors Without Borders operate in war zones. They run on adrenaline.

Labour is the biggest expense in hospitals. At 75 percent of hospital costs, it is not surprising that staffing is a key target of cost reductions [Ontario Hospital Association 1998: 89]. Household members think that cuts to hospitals staff are unacceptable, since patients rely on these people when they are most in need. Participants say that saving money by laying off staff and changing the skill requirements of care providers costs patients and health care workers dearly.

Frank and Michael recount their experiences in hospital last year. They explain that nurses, in particular, are overworked and under-resourced. Frank says that:

The effects of the cutbacks were really clear. It was like the nursing team was on a rat wheel, racing constantly. The nurses were great – when they were able to respond. But you could press the buzzer and you might be waiting half an hour before you'd get someone to come to your room. Now, if Michael had a critical emergency during that time and I hadn't been there or someone else hadn't been there to be able to run to the desk and say: "we've got something going on here," he could have died in that bed and no one would have known.

Rosa is separated and lives with her daughter in Toronto. She notes:

If I cut my foot or hit my head, I want to be able to go to the hospital. I don't want to have to think that I'm going to be sitting in the emergency room or lying on some gurney, bleeding all over the place. I worry that an underquali-

fied staff person who is not even a Registered Nurse's Assistant, but an untrained nurse's helper, is going to be assisting.

Rosa's concerns are reinforced by Janet who says that deskilling compromises care and cuts costs in the wrong places. Janet lives with her husband Christopher. Christopher is now working two part-time nursing jobs in two regional hospitals. Because he works night shifts, Christopher was not able to participate in our second interview, so Janet explained what is happening to staff in his hospital. She says:

This year, Christopher was laid off as a nurse at the hospital. He transferred into the kitchen because a job is a job to him. At the hospital, they've gone from having health care aides to having personal support workers. A personal support worker gets eight months of training, total. They are phasing out RNs [Registered Nurses] and the RPNs [Registered Practical Nurses] are doing the RNs' work. The health care aides are taking the RPNs' work. With eight months of training, health care aides are now doing vitals and catheter care. Soon a personal support worker will likely be doing this work, without a certificate.

Hospitals have attempted to cut costs by shifting more services to outpatient care, decreasing hospital stays, laying off staff or shifting to what Pat Armstrong and Hugh Armstrong call the "lowest cost care provider" [1996: 140-142]. Hospital services such as cleaning, laundry and food preparation, called 'hotel services,' have in many cases been contracted to private companies. Many participants complain that hospitals are less clean, food is inferior and linen is in shorter supply. While in hospital, Teresa noticed that corners were being cut in staffing and services:

I saw cleaning staff delivering and picking up food trays. That really freaked me out because somebody who just washed my toilet was delivering my food tray.

In a later interview, Christopher explained that time is taken away from patient care because of cuts in staff and resources:

I think that nurses give the best care that they can give. They don't have much time to deal with each patient. I work on a busy medical floor and so we have to prioritize patients. If one patient can do a little bit more herself than another, then I'm going to spend time with the person who can't do as much for herself. Some families look at that as: "You're not looking after my mom." It is very hard. On top of that, the hospital is cutting back on supplies. There's a lot of things you might want to bring from home now, if you're staying in the hospital, like soap, cream and powder.

Christopher went on to explain that cost-cutting strategies end up costing more in the long term:

The adult diapers that we used to use in the hospital were the Attends brand, that's a brand name. They were really good, much better than others. The hospital has cut back, they've gone to what I would call an inferior brand. They don't work as well as they should. Patients should be able to urinate three times and the diaper will hold it, and it doesn't work. People are uncomfortable and unclean. It's not cost effective. You end up changing the whole bed and patient. You use more linen instead. Time changing a bed is time better spent giving somebody a back rub. But we don't have time to do that anymore. People really notice it.

Christopher's experiences with budget and staffing cuts in hospitals are echoed by the

Health Services Restructuring Commission. In 1998, the Chair of the Commission said that the strategy of cutting funding and then telling hospitals to find ways to be more efficient, rather than planning change, is expensive and less efficient [Coutts 1998a: A7].

Downloading the costs of hospital restructuring

Hospitals are not only trying to save money through staffing, service and infrastructure changes, but they also are trying to recoup costs through privatizing some services, increasing fees or fundraising. After a recent hospital stay, Leo, a Toronto father of two, was solicited to donate money to the hospital:

The hospital called me a number of times to ask me to donate money. The first time I gave \$25, the second time I gave another \$25. They asked if I could leave something to the hospital in my will. I don't agree with this. What's going on, why are they asking me for so much money? They never asked me for money before, but the government is cutting funding and they need money. So I said, I'm not going to support them anymore, let them complain to the government.

Olivia, who was undergoing chemotherapy treatment for cancer, describes how hospitals are charging increased rates for parking in an attempt to raise funds. She explains what this means for patients who have restricted mobility:

We cancer patients often cannot walk long distances. And yet the hospital is not providing the necessary parking for us. It's there, but you have to pay \$28. It is the government that is responsible for the agony that patients go through. They should be providing more money for the hospitals so that they don't have to raise

money through parking, which is what they are doing.

In 1996-97, the Ministry of Health provided 85 percent of total hospital revenues, while the other 15 percent was obtained through co-payments by patients or third parties, and commercial activities such as parking. Hospitals are using these funds to pay for restructuring and operating costs [Ontario Hospital Association 1998: 75].

FROM HOSPITALS TO HOMES

Families as caregivers

Members of households who provided care or required ongoing care speak of how restructured health care services put additional pressure on families to assume more of the caring responsibilities that once were publicly provided. In light of chronic understaffing in hospitals, some participants felt it necessary to form care networks composed of family and friends. Michael and his partner, Frank, created such a network in advance of Michael's hospitalization:

We had a team of people – very close friends – who worked with me and provided care for me in the hospital for the first week. We called them the inner circle. The quality of my care was enhanced by the care team.

One northern Ontario participant explained that his household also took on in-hospital care. When we first spoke to Bert, a primary resource worker, we learned that his family organized a caring network that took turns going to the hospital to care for his elderly mother:

In this day and age, if somebody didn't go to the hospital to feed my mother, she would starve to death. The hospital is so understaffed now

that they don't have the time to feed patients. So somebody in the patient's family either feeds them or they don't get fed.

However, those households that establish caring arrangements find that these networks are easily exhausted and are not feasible long-term strategies to deal with ongoing health care needs. Even the most devoted of caregivers succumb to the exhaustion of providing care. Frank explains:

I couldn't deal with it. I was ashamed of myself for not having more strength or emotional capacity. I felt like a failure as a partner, as a caregiver. It was awful. And it took me awhile even to admit to myself that it was going on.

Similarly, Victoria, a social worker in Ottawa, feels strained under the burden of managing her elderly parents' care and her ongoing treatment for a serious medical condition. She describes how emotionally drained she felt after leaving her mother in the hospital:

I started on my way back to work in the afternoon. Driving down the road, I was teary. I told myself: She's got to be all right because I just can't juggle one more thing. I thought: Who's taking care of me? There's nobody taking care of me.

For Victoria and Frank, providing care to people with whom they have close relationships means that for both themselves and those receiving care, feeling frustrated or exhausted strains their profoundly important relationships.

Cheryl, who lives in southwestern Ontario with her husband and two young boys, is coping with being a parent, trying to secure paid work and struggling to take care of her elderly parents. She explains:

If I were working for pay, at least a part-time job, I suppose I could say: “Dad, I’m sorry but I have to work, I just can’t go to see Mom today.” But I don’t have work, and he feels threatened by my working because he thinks I won’t be available for the family. Last week, I told my husband, Paul, that I’ve really had enough. I said I just can’t take care of you, my mother and my father, the cat and the kids. I’ve had it.

For Cheryl, as for many women, the burden of caring falls disproportionately on her shoulders. The process of health care restructuring in Ontario is increasing the demands placed on women as resources to alleviate or share this burden are decreasing.

The assumption that patients would be better off recovering at home presupposes that there is someone at home with the time, skills and capacity to provide care. Liz’s experience demonstrates what can happen when the option of relying on family or friends is not available:

I came home on the streetcar because I only had enough money to take a taxi one way. And since I was going in for surgery before it was daylight, I thought I’d be okay to take the streetcar home. I got off and I had to go in and get a few groceries, some bread and stuff. And when I went into the store, the lady said: “You look awful, you look like you’re going to faint any minute.” And I said: “No, no. I just got out of the hospital, I had an operation.” She said: “Are you going to make it home?” And it was just down the end of the street. And I said: “Oh yeah, I think I’m going to be okay.” But you know, ordinarily they keep you in a couple of days after surgery. Soon it’s going to get that they just wheel you in, do it and wheel you back out again. They don’t have the beds available for a person to properly recuperate.

Even when familial support exists, it is not necessarily drawn on, often for fear that this will put too much pressure on key relationships in people’s lives. Mark describes how he would pawn household items rather than ask his parents for money to cover the cost of his drug medication: “I’d rather take something to a hock shop, and pay for my pills, than say: “Hey Mom and Dad, can I borrow money to fill my prescription?”

The costs of providing health and health-related care may shift from the formal health care sector to the home, but they never disappear. Household participants’ experiences illustrate that such costs are now being absorbed at the level of the family. As Sabrina’s experience attests, the stresses in the health care system are increasing the stress on Ontario’s families:

People I work with have support circles. I just don’t know how they go on. There is so much pressure on families to provide such a high amount of support because the government is backing out. When families do get money or assistance, it amounts to grovelling. They are taxed to the hilt, and people are asking them to give more. They can’t.

The downloading of caring work to the family shifts work from the paid labour of women in hospitals to the unpaid labour of women in homes. This shift includes the administration of medicines and the use of medical equipment. Anne, a low-income parent with children who have substantial health care needs, tells us that she has to manage multiple and changing medical needs as well as administer drugs with increasingly high-tech machinery:

All of my kids have to use the aerochamber for their asthma now. It is a quicker way of administering their medicine. I give it to each of them

through a machine. What's really difficult is that I have to keep track of a whole cupboardful of medicine. I have more in the fridge. My kids are so sick, and it's so hard for me and for them. I worry that I will lose track of who gets what medicine.

Olivia's story: in between hospitals and homes

When we first spoke with Olivia in the winter of 1996, she and her husband, Gary, and teenage daughter, Gina, had moved from Metro Toronto to the surrounding Greater Toronto Area. While meant to offset the high cost of living in Toronto, the move presented other obstacles to work, school, and family and community supports. By the time of our first interview in May of 1997, Olivia had been diagnosed with breast cancer. Despite her illness, Olivia wanted to continue to participate in the *Speaking Out* Project, seeing the latter as an opportunity to contribute to the ongoing dialogue about change in this province.

Olivia's story demonstrates the lack of a coordinated bridge between hospital care and long-term care. Her experience and insight underscore the crisis in acute care and home care in the province. Olivia's story provides a cross-sectoral perspective on health care. Sadly, Olivia lost her battle with cancer and died during the writing of this report, but the telling of her story ensures that her experiences are not forgotten.

Even with an acute diagnosis, Olivia waited three weeks between her diagnosis and treatment: "*It actually was a question of time,*" she explained. "*The oncologist didn't have any other opening for me. I had to wait three weeks after the suggestion that I might have had a tumour.*" Olivia's husband, Gary, expresses the fear of other household participants waiting for

specialized care: "*Would the time spent waiting have made all the difference?*"

While undergoing treatment, Olivia described how hospital understaffing undermined the quality of care she received:

Initially, I was confident that the support system that I was establishing outside of family and friends was going to work very, very well. After two and a half weeks with the Oncology Clinic, I discovered that it didn't work well. The reason is that there is definitely not enough staff to take care of the needs of cancer patients. There's not enough time for staff to provide the services that they would like to provide, and that we, as cancer patients, require.

Olivia explained that the needs of cancer patients are complex, extending beyond medical procedures such as radiation and chemotherapy. With higher demands being placed on specialists and nurses, the dignity of the patient is often replaced with an assembly line approach to health care:

My last visit at the hospital was a very, very traumatic one. I saw rows of patients waiting to get their blood tests done. The waiting period was far too long, the conditions under which we were waiting were very claustrophobic and oppressive.

In October of 1998, Olivia's struggle to get the kind of care and relationships she needed was dealt a blow as a result of the Health Services Restructuring Commission's recommendation to merge her oncology unit with another hospital. Olivia's biggest fear was over the continuity of her care:

I've experienced compassion and care and attentiveness these past couple of years from the doctors and nurses here and I expect that to

continue. I don't want to lose that. I don't want to have to fight for something that I believe a person in my position deserves. A right to choose where and with whom I get my treatment. Everybody should have the right to choose, but in daily life we struggle for it.

Olivia questioned whether the increased patient loads would be met with growth in the number of health care professionals. In a follow-up telephone conversation in January 1999 regarding the impact of hospital mergers, she spoke of longer waits for treatment and her fears of understaffing. Olivia's concerns at that time also extended beyond the issue of quality of care to her loss of control over that care.

In between hospital treatments, a nurse and physiotherapist would visit Olivia once a week. The at-home nursing care was disrupted by a labour dispute between the home care nurses and the province. The loss of the support of home care had implications for Olivia's health and for the well-being of her family which was providing care in place of the nurse. Olivia explains:

It's obvious that care has shifted, more towards home care than hospital care. And there are advantages and disadvantages to that. Sick people like myself do need to have a professional who can do home visits. I also need to feel as though it's a giving thing, more than me taking. If I feel like I am only taking, then I feel humiliated. When someone is in the hospital, they don't feel humiliated like that because, there, staff are obligated to give you care, and that's exactly how it is perceived. But at home it is different.

For Olivia, the reliance on family members to provide care was a mixed blessing: The comfort of home was accompanied by fear that her family members lacked the skills or capac-

ity to provide care and that the caring work burdened her family members.

Olivia's experience with acute hospital care and home care reflect changes in staffing, funding and infrastructure that affect the quality of care received. Moving quickly from hospital to community-based care, without adequate planning, coordination and universality of access, undermines the quality of health care.

Long-term care

The long-term care sector is a complex set of services and institutions. Unlike hospitals, it is not easily recognizable to most Ontarians. Its lack of visibility is partly a result of service provision taking place in peoples' homes

What is Long-Term Care?

The major components of the long-term care system include:

- services in nursing homes, homes for the aged and for people who require 24 hour on-site nursing services.
- community services that support people of all ages who need health services at home (often referred to as home care), including in-home visiting nurses, therapists, homemakers, day programs for seniors, supportive housing, Meals-on-Wheels and attendant services for people with disabilities.

Community Care Access Centres (CCACs) coordinate access to services (such as homemaking, nursing and therapy) to people at home and provide some long-term care facility placement.

Source: Government of Ontario (1998).

(in the case of community-based care) or in residential facilities (in the case of nursing homes or homes for the aged). Many Ontarians do not associate some of the services provided through long-term care as being part of the formal health care system.

What Are Community Care Access Centres (CCACs)?

Until 1996, there were about 1,200 organizations in Ontario offering home nursing and home-making services. The provincial government purchased their services through 74 Placement Coordination Services and regional Home Care Programs.

In 1996, the Minister of Health announced that the existing 38 Home Care Programs, which arranged nursing visits and homemaking services, and 36 Placement Coordination Services, which managed admissions into long-term care facilities, would be consolidated into 43 Community Care Access Centres. CCACs, which became operational in 1997, are not-for-profit corporations governed by volunteer boards of directors.

According to the Ministry of Health, CCACs:

- provide information on available services and programs
- conduct individual assessments
- determine clients' eligibility for services
- plan a program of care
- arrange for services to be delivered.

Since April 1, 1999, all of Ontario's home care contracts have been open for bidding and are awarded by the CCACs.

Source: Provincial Auditor of Ontario (1998: 103-234); Ontario Ministry of Health (1998); Picard (1999a: A7; 1999b: A12, 13).

The aim of long-term care is “to provide a continuum of health services and support” that improves the quality of life of seniors, people with continuing care needs and children with disabilities [Government of Ontario 1998]. Household members raised concerns about the government's strategy of downsizing hospitals without ensuring that community supports were in place. The lack of coordination between sectors – hospitals, doctors and long-term care – means that the long-term care sector has to deal with increased demand for services without the planning, staff or legislative authority to do so effectively.

Sara works in the health care sector. She summarizes some of the problems she sees with Ontario's 43 recently created Community Care Access Centres (CCACs):

The provincial government said that one of the problems was that some CCACs had too much money and others had too little, so they wanted to even out funding. This is the big problem in home care: They are evening out funding, but to the lowest level!

Sara continues:

CCACs don't only need more money. The government talks about accountability in providing quality care. Yet they are not collecting data on quality of life issues. You have to know these things if somebody wants to remain in the community. You must know what their activities of daily living are after leaving the hospital. Can they bathe? Can they dress? Can they prepare food? What is happening is that you are sending out a more acute patient.

Unlike hospital care, which is governed by the *Canada Health Act* – federal legislation that sets national conditions for medicare and guarantees access to medically necessary serv-

ices – long-term care is not governed by universality of access or conditions governing care.

Michael's experience demonstrates the problems with non-universal care. For Michael, getting home care was straightforward, but keeping it was not. He says that the home care nurse had to advocate to her supervisor on his behalf in order for him to keep his care:

I would phone the home care nurse and I would tell her that I had just received another call from her office and they want to discharge me again. They wanted to discharge me after I was home for ten days after serious surgery. All they wanted to know is: Can you do your own personal care, can you do the necessary things? If I could, I was no longer eligible.

Sara says that, in her experience, cash-strapped CCACs are directing their limited funding to acute patients who need more intensive types of care – like Michael, at least in the ten days after his surgery – at the expense of those who require less intensive home support. In many cases, this problem means that outpatients who require care for shorter periods of time get prioritized over elderly people who have longer-term at-home care needs. The very people long-term care was set up to serve are being forced to the back of the line.

Sara continues:

The acuity of people using home care has increased. They're doing dialysis, they're doing IV drips. They're doing a lot of intensive types of nursing activities in home care. But some of that care is coming at the expense of other people who could probably just use a little home care service. The less acute get cut. This places a lot of burden on families. What's happening now is you have daughters quitting work to take care of their parents.

What Governs Long-Term Care Services?

In 1995, the *Long-Term Care Act* (Bill 173) was proclaimed under the previous NDP government. However, because there are no regulations, eligibility is not addressed, inspections of long-term care community service agencies are not taking place, quality management and monitoring systems have not been established and complaints from service recipients are not subject to formal review. Instead of putting regulations in place, the current government relies on ad hoc service agreements with CCACs.

In 1998, the provincial Auditor noted that eligibility criteria for community care services were inconsistent, often denying people access to services like homemaking. Further, the Ministry of Health denies that CCACs are covered by the *Long-Term Care Act* or that people who seek long-term care have any rights under the legislation, even the right to appeal a CCAC decision. At present, two of the 43 CCACs are covered by the legislation; the other 41 are not.

The lack of regulations and the denial of a legal basis for receiving services leave those who require care beyond hospitals and doctors subject to arbitrary decisions based on funding.

Source: Meade (1999); Health Services Appeal Board (1999); Provincial Auditor of Ontario (1998: 104, 109-110, 117).

In April of 1998, the provincial government announced a spending increase of \$1.2 billion for long-term care services over eight years, later reduced to six years. In 1999, an annual funding increase of \$18.1 million for long-term community-based service agencies was announced. According to Premier Harris, this money represents savings from other areas where health care spending has been cut [Coutts 1998b: A3]. While the sector urgently requires

new spending, members of households with experience in long-term care raise important concerns about its quality, accessibility and affordability, particularly if new spending comes as a result of cuts to other areas of health care and it comes after, rather than before, those cuts.

Long-term residential care and the various community-based services, such as visiting nurses or home care support, are the two areas about which household members spoke the most. Cheryl and Paul's story recounts their struggle to get quality care for an aging parent in the transition from home to hospital to long-term residential care.

Cheryl and Paul's story

Cheryl and Paul live in a southwestern Ontario city with their two children. Paul works as a teacher, and Cheryl has employment experience in a number of areas, including retail and homemaking services. Cheryl and Paul are university educated and Cheryl has training in social work. When we first interviewed them in June 1997, neither raised the care of their parents as significant concerns in their lives. In February 1998, they told us that they were increasingly worried about the state of health care in the province. Paul's father suffered a stroke and had to wait a long time in the emergency room to receive care and be admitted. Cheryl's mother had been in the hospital and was now receiving home care services, with which they were reasonably satisfied at that time.

Eight months later, caring for Cheryl's mother was a significant part of their daily lives and the stress of getting her the kind of care she required was taking a toll. Paul's father had been diagnosed with Alzheimer's disease and both of his parents had moved to another Ontario city

Long-Term Care Funding

Provincial spending on long-term care has increased over the last 4 years: \$224 million (10 percent) more was spent in 1997-98 than was planned for 1995-96. Over the same period, however, hospitals lost \$575 million, putting more pressure on the long-term care system. The Health Services Restructuring Commission made an appeal to stop cutting hospital funding while the long-term care system was being restructured. "During the implementation period," wrote the HSRC, "it will be critical to maintain the resources currently being used by chronic and acute hospitals for patients receiving long-term care. Hospitals should not be allowed to close beds and/or programs arbitrarily before alternative programs are available."

Source: Ontario Ministry of Finance (1998a); Ontario Management Board Secretariat (1995); Health Services Restructuring Commission (1998a: 44).

to be closer to Paul's sister, who could provide them with some assistance and support. Cheryl says that she and Paul could not have taken on the care of Paul's parents in addition to her own parents.

Cheryl's mother entered a nursing home in 1998. She was on a waiting list for several months and was in hospital during that time. In late 1998, she was on a two-year waiting list for another nursing home that is reputed to provide better care. Cheryl visits her mother almost every day and also provides some care for her father who now lives alone. She describes her stress and fatigue levels as extremely high. Cheryl says that dealing with social workers, health care workers and doctors is onerous, both emotionally and in terms of trying to obtain care and services for her mother. She recounts that one of the administrators at her mother's nursing home phoned her mother's doctor to tell him

that they were concerned that Cheryl seemed very stressed. She explains:

Why shouldn't I be stressed about my mother's care and her health? It's like I'm supposed to be a professional daughter. They are professionals, but I don't have to be a professional. I don't feel satisfied with the care she is getting and with the care I am providing her. It's just the best I can get for her.

Cheryl says that she is not sure what her expectations should be with respect to her mother's care:

I can't tell if I'm being fair or not. She's my mother. But I go there and she's not dressed properly and they've lost her clothes. Everyone is nice, but it's the system. For example, there is a really nice area to eat, but you have to be high-functioning for that. So when my mother moved in there, they put her in another place to eat. I said: "Why are you putting her here?" And they said: "Well, we are assessing her." It's a hierarchy, so if you're okay, it's like the rest of society – you get to eat in the lounge with flowers on the table, and you can look out the windows. And the worse off you are, the less there is. So my mother is not at the very bottom, but she's not where I want her to be.

Cheryl describes the care her mother is receiving:

I'm trying to be reasonable, but sometimes I just don't know what to think. I went to visit her one night, and she had to go to the bathroom, and they just put her to bed. I said, it's 7:00 at night, and I'm visiting. I know it's convenient for you to put her to bed now, because she's been to the bathroom, but couldn't you wait? And they say to me that she likes to go to bed now, and I think, oh yeah, I just bet. "This is

what your mother wants," they say. And then I went there at 4:00 p.m., and she had to go to the bathroom, so they put her to bed. I said she only had her dinner at ten to 4:00, it seems a little early to me. I understand that she's tired at night, but what the hell is going on here lady? What are you talking about putting her to bed, this is the summer and it's 4:00 p.m. This is supposed to be such a great place? They did a real PR job on me, saying: "I know it's upsetting for you." Well you know, the reason it's upsetting for me is how she is being treated.

Cheryl's story is not uncommon in Ontario. Although all nursing homes must meet certain provincial standards, these do not guarantee that residents will experience the levels of care they need to keep them well. Provincial money is targeted to increase the availability of places in nursing homes and homes for the aged. However, decreased standards of care, hospital bed closures and growing waiting lists for long-term residential care mean that funding is likely inadequate to deal with the needs of elderly Ontarians and those with special needs. The announced closure of 3,506 chronic care beds in hospitals means that high needs patients are being moved into long-term care facilities, which may lack the level of medical care that some of these patients require.

More funding for the residential sector of long-term care does not necessarily translate into improved standards of care.⁴ The Health Services Restructuring Commission's recommendations for 'reinvestments' into long-term care of savings generated from hospital restructuring did not take into account those on waiting lists or those denied services. In 1998, the waiting list for long-term residential care was 18,000 people, an increase of 2,000 from the previous year [Chamberlain 1998: F1, F5]. Further, of the promised 20,000 new beds, no mention was made that at least 4,875 would replace beds used

by long-term care patients in acute and chronic care. (See Table 4.)

Josie tells another side of the long-term residential care story and agrees with Cheryl’s concern that the care is simply not there. Josie lives with her adult daughter and grandchildren in the Greater Toronto Area and has been a nursing aide in a municipally-run home for the aged for over 20 years:

Quite often, I’ll have 25 residents to care for. I put them to bed far too fast. Quite often, I can’t give them a bath. If they argue and say that they don’t want a bath tonight, I used to be able to sit there, chat with them and talk them into having a bath. Now, I don’t have the time to do that. You don’t want your bath? That’s too bad. Bye. I have to go on to somebody else. That’s what it boils down to. Residents fall and break their hips because we don’t have time to go and check on them, to find them. We found a resident the other night on the floor. She had no injury, but her knees were already bruised by the time we found her. She said she had been there on her knees for about four hours.

Christopher worked in a nursing home as a nursing aide last year. He explains that get-

ting a residential placement can take a long time and can disrupt a person’s life substantially:

You have a ‘choice’ of six nursing homes. When a bed becomes available, it doesn’t matter if it isn’t the one you want to go to. Say the whole family lives in Bristol, you’ve lived in Bristol all your life, all of a sudden a nursing home bed is available in Trafalgar, so that’s where you have to go. You have to go there, and then you have to wait to get back into your own area. So they would move that person sometimes two or three times before they would get them settled back in their own community.

Christopher echoes Josie’s experience that once residents get into a long-term care facility, the quality of care is often substandard. He told us that when he was hired as a nurse at a nursing home, he refused the position because he felt the possibility for drug error resulting from understaffing was too high. He explained that he would not put his licence on the line and instead took a lower paying position as a nursing assistant. He cautions:

I worked in a nursing home and I would really have to investigate before I put my parents in one. Their food is inferior, they never seem to

Table 4
Long-Term Care Beds⁵

	total long-term care beds	nursing home/homes for the aged beds	chronic care beds	other hospital beds
1995-96	62,347	57,472	3,562	1,313
2004-05	77,000	77,000	0	0
difference	14,653	19,528	-3,562	-1,313

Source: Health Services Restructuring Commission (1998a: 114, 121); Ontario Ministry of Health (1999).

have enough supplies to work with, the workers are overworked. They have no air conditioning in these places except in the dining rooms. It's unbelievably stifling hot in the summer time. Their beds are uncomfortable. If I was paying \$1,400 or \$1,500 a month, and that's sort of a basic price, I would want to have a little bit more than what they've got. It was a real eye-opener for me coming out of hospitals, because the government doesn't spend money on the nursing homes.

Victoria explains the community-based care piece of the long-term care puzzle. Like long-term residential care, the story of in-home care is largely one of cost savings, which means that standards are decreasing while workloads – for both paid workers and family members – are increasing [Barber 1998: A7].

Victoria's story

Victoria is a 49-year-old single mother who lives in Ottawa (her daughter is away at university). Victoria has completed a graduate degree and works full-time in an urban hospital.

When we first spoke with Victoria in June 1997, her parents were living in their own apartment in Ottawa and receiving support from each of their three children. While they were independent, Victoria's father recently had pneumonia and, given that her mother is elderly and diabetic, the family decided to use home care services for support around the house. Up to this point, Victoria's father consistently had refused any kind of outside help, but the family finally convinced him that it was necessary and worthwhile. At that time, Victoria described home care as “*marvellous*.”

By 1998, the situation was very different. Victoria described the problem of her mother caring for her father and the inadequacy of home care coverage:

The home care case manager said: “Yes, I'm hearing loud and clear from the treatment team that what he needs is more services, and we just cut your hours by 33 percent because of budget cuts. We know it's terrible and so you should go to the private sector and pay.” So we did that, and we had 24-hour nursing care for him because about a week after the care conference, he got shingles, he couldn't feed himself and he became incontinent, bowel and bladder both. We needed something. My mother – this little old lady with her diabetes who is exhausted – had been up for 26 hours because my father was calling out. A hospital-in-a-home is a great concept, but it doesn't work. My mother had been doing laundry, because my father wouldn't wear a diaper. They had gone through all the sheets, all the towels, all the long underwear, everything that they could use. The nurse was doing the care, supposedly freeing up my mother to be resting. That's a great concept. But she was doing the laundry.

Victoria's experience points to a failure in the provision of home care in Ontario: Without the formal protection of the *Canada Health Act* or legislation like the *Long-Term Care Act*, the availability of, access to and quality of home care vary considerably across the province. With patients being sent home ‘quicker and sicker’ and with elderly populations living independently without adequate support, people who need care may not be getting it or are being forced to buy it privately.

Janet, who runs a cleaning business in southeastern Ontario, tells us that she had to call

Community-Based Services

Although more money is being spent on long-term care, less money is being spent on home-making services. Spending on professional services (including nursing and physiotherapists) was up by 22 percent in 1997-98 from planned spending in 1995-96, but spending on homemakers (who provide personal care and home support services) was down by 2 percent. Each year, CCACs, confronted with increased demand and more people released earlier from hospitals than in the past, divert money from helping people bathe and prepare meals to helping people with acute medical needs. More funding for community services will not lead inevitably to care provided at the same level as is provided in hospitals. Homemaking services in 1998-99 were proposed to fall to 30 percent of community-based services budgets, from their previous proposed levels of 33 and 34 percent.

Source: Ontario Management Board Secretariat (1995, 1996, 1997, 1998); Ontario Ministry of Finance (1996, 1997, 1998a).

a home care service provider because a client of hers was not receiving adequate care:

I have a client who had a home care service provider come in. He was on heavy-duty pain-killers and was totally disoriented. One morning, I went up to find that his home care worker was coming in a half hour late and leaving 15 minutes early, which gives her 20 minutes to be there. I said to my client: "Noah, you have bedsores." So I took it upon myself to go out and buy a hand-held showerhead and a shower stool. I showered him once. Last Thursday, they cut off his home care. If someone doesn't have the support of family, they'll be sick and alone. That's our health care system: They're pushing home care because it's cheaper, and the quality of care sucks.

For those household members with chronic needs or who care for a parent requiring nursing care, the waiting lists, user fees and costs associated with home and residential care are very difficult to deal with. Some household members, like Jenny, did not receive information about home care while in hospital. Others, such as Michael, had to fight to keep home care. Still others, like Cheryl, suffered through months of waiting for a long-term residential care bed to open up, only to discover that the quality and standard of care provided are inadequate. Finally, some household members, such as Victoria, had to hire providers privately.

Long-term care is a rapidly expanding part of the health care system. The focus in long-term care has been on keeping costs down by limiting eligibility for services. Unlike hospitals, there is no legislation guaranteeing access to care. There is little research or evidence to support the notion that home care, as currently structured, is more effective than hospital-based care.⁶ If there are savings, they may result only because the costs are shifted onto families and women in particular.

TARGETING OF SERVICES: DECIDING WHO WILL BE HEALTHY

Unnecessary care? decreasing access, increasing costs

Julie, a researcher with a disability living in Toronto, recounts how she has to make more out-of-pocket payments as services are deinsured from OHIP. She explains:

People now have to pay to get doctors' notes. That's an issue especially for lots of people with disabilities who need a doctor's note to get transportation or to get assistive devices. Those

small things which were taken for granted, now you've got to pay \$10 a visit.

Twenty-two services or procedures deemed not 'medically necessary' for the diagnosis, prevention or treatment of illness have been deinsured [Ontario Ministry of Health and Ontario Medical Association 1998]. Under the *Canada Health Act*, there can be no charge for medically necessary services. The term 'medically necessary' is ambiguous and is not defined in the *Act*. As Julie illustrated, even a minor medical service is useful for some people some of the time.

Veronica, a school bus driver and single parent of two children with chronic care needs, found that the criterion of 'medically necessary' rests more on cost considerations than on patient care:

I called the ambulance and, by the time the attendants came, my son's colour had come back. I was told I was overreacting. The attendant said: "You're overreacting, he's just got a cold, everybody has this virus, and there's nothing we can do for him. If we take him to the hospital, you're going to be hit with a \$240 bill if the doctor decides that the ambulance was not necessary."

Shortly after the ambulance attendants left, Veronica's son, Henry, relapsed. On the ambulance's second visit, Veronica insisted he be taken to the hospital where a doctor could assess the severity of his condition. The \$240 fee the ambulance attendant referred to is charged to Ontario residents without a valid OHIP card or when ambulance service is found to be not medically necessary. As Veronica's experience illustrates, Ontarians are now involved in a guessing game about when an emergency is deemed serious enough for the use of ambulance services. This notion of inappro-

priate utilization, implicit within the concept 'medically necessary,' is challenged by Jessie, a community development worker living in northern Ontario, who asks rhetorically: "*How do sick people waste health care?*"

Instead of addressing the real problem – the lack of accessible alternatives to emergency room care – attention has been shifted to those who use (or are said to abuse) the system as the alleged source of the problem (old people, bed blockers and, in this case, overanxious mothers). Veronica feels less entitled to services and now sees cost as a determining factor in whether her children receive treatment.

Amy, a full-time college student and mother of three children, speaks about household members' more general sense that increasingly they are being 'nickel and dimed:'

I paid for a medical report to get in my program at school. I paid for the doctor to fill out forms for housing. I paid for forms for an assistive device. Any kind of form, you name it, I've paid for it.

The Ontario Medical Association's response to the newly deinsured services was to recommend fee increases that are roughly 65 percent higher than what physicians were paid under the most recent OHIP schedule of benefits [Priest 1998: A4]. While decreasing the number of services from public payment, deinsured services shift costs to personal out-of-pocket expenses or private insurance. Liz explains: "*I didn't know I had to pay for my knee immobilizer, it was quite a surprise to me.*" Reading from a schedule of fees she obtained at the hospital, Liz continues:

Crutches are \$25, a cane is \$15, a cervical collar is \$20, a knee immobilizer is \$40 and so on. They make you sign an invoice before they will

give you the equipment you require. The invoice says: "I have been advised of the cost of the item provided and I'm aware that I will be billed for it."

Although Ontario always has had a mix of public and private spending in its health system, according to the Canadian Institute for Health Information the public sector share of total health care expenditure continues to decline [1998: ii]. There is evidence to support participants' accounts of rising personal costs, whether they be fees for notes or services or costs such as bringing Kleenex to hospitals. After factoring out the private spending on health services that they always have had to pay for (such as dentists, eyeglasses and the regular use of prescription drugs), Ontarians are now spending an average of \$35.99 more per person, per year for health care than they did in 1995 [Ontario Alternative Budget 1999: 4].

Despite the intent of reducing unnecessary use, charging user fees – such as ambulance fees – does not reduce overall use of the system to any significant extent [Rachlis and Kushner 1994: 154-160]. For those higher-income households with access to private health insurance, these shifting costs are more easily absorbed. Victoria, a social worker in Ottawa, requires the use of the Assistive Devices Program (ADP). ADP is a provincially funded program that provides financial assistance through grants or maximum contributions for devices to people with long-term physical disabilities. Victoria is able to offset additional costs of her care because of her employment status and private health coverage:

ADP is eroding all the time because they haven't increased people's grants, and it's no longer covering 75 percent for most people who have ongoing needs. But for me, I don't stop to count

it up, because I don't have to. I'm lucky enough to be in a financial position where I just put the cheque in the bank. I don't know where I stand vis-à-vis my percentage.

The burden of higher private expenditure does not fall evenly. For those Ontarians who are unable to produce a valid health card, regulations now state that they will have to pay the full cost of their care or be denied treatment unless it is an emergency [Ontario Ministry of Health 1997]. Richard, who has AIDS and lives in the Greater Toronto Area, lost his health card. He received a temporary replacement but was denied his regular hospital treatment after his card expired. Although hospital staff knew him well, they were powerless to exercise any discretion because of the new Ministry of Health regulation that no longer honours 'good faith' payment claims. As a result, Richard's care was temporarily disrupted until he spent \$30 (a significant portion of his fixed income) to replace his birth certificate in order to get a new health card. As Richard's story reveals, making services more conditional – in this case, upon presenting a valid health card – may complicate and unnecessarily delay medical treatment for those who are least able to pay.

Household members reveal that reducing public costs by purging the health care sector of so-called inappropriate expenditures forces Ontarians to make impossible choices around critical aspects of their care. For Teresa, a low-income woman with chronic health needs, making services conditional on one's ability to pay or restricting eligibility means she goes without essential services. Teresa, who requires the use of assistive devices, explains:

You were allowed to get replacement pieces whenever you needed it, and ADP [the Assistive Devices Program] would cover it. ADP no

longer covers replacements as needed, they'll only cover two pieces a year. So, if you don't get your two in a year, then you're out of luck. I require a hose and a mask to help me breathe. If one comes apart or it breaks, or whatever happens, now they don't fund it. My pieces don't last that long because I use them every night, and two a year is not enough.

She continues:

I've been lucky that this mask has been lasting a long time, but that's because I've neglected cleaning it. It's supposed to be cleaned out because I'm breathing in this thing, but it comes apart if you clean it too often.

The shifting of health care costs onto individuals may, as Mark's story reveals, increase self-diagnosis and treatment. Mark, a member of a low-income, northern Ontario household with no private health insurance coverage, agreed to participate in a clinical drug trial after a brief hospital stay. The cost of the treatment proved so prohibitive that Mark began to manipulate the prescribed dosage in an attempt to control costs:

I had to change dosage, because they first gave me dosages of one milligram, and you pay almost the same price as if you were to get five milligrams. You pay by pill, not by the dosage. And my dosage always changes, so I asked for the larger dosage because I figured out that if I break the pill in half or only take so much of the dosage, I reduce my cost.

Had Mark remained in the hospital, his care would have been supervised and he would not have had to incur any of the cost of his treatment.

These household experiences point to a health care reform agenda that is not about mak-

ing health services more responsive to the needs of Ontarians. The provincial government's strategy has been to look for ways to reduce costs in the publicly funded health care system, through the deinsurance of procedures and services. Patrick, a single man living in the Greater Toronto Area, concludes that co-payments and deinsured services mean: "I'll be using the doctor less frequently than I have before." Restricting access and making citizens pay more for services erodes publicly provided health care.

Uncovering Ontarians: OHIP, private insurance and extended coverage

Patrick, who does not have access to health or dental benefits through his employer, is concerned that current trends in the health sector are narrowing OHIP's [Ontario Health Insurance Plan, Ontario's medicare system] already limited coverage:

The thing about the OHIP system is that it is limited; we have free coverage for doctors and hospitals, but even that's changing. It's not free coverage for chiropractors – you have to pay on top of whatever OHIP is subsidizing. Dental is not even subsidized at all and that's part of the health care system. Your nutritionist, a holistic approach, a physiotherapist, that's not covered. That's not a health care system: That's wrong. It should be included in health care instead of somebody's insurance policy.

Veronica and her children lost access to private health insurance when her ex-partner changed employers. She explains the importance of extended coverage:

If you don't have your own private insurance in place, you run the risk of getting substandard care. On the private insurance plan, everything was covered, [including] brand new medica-

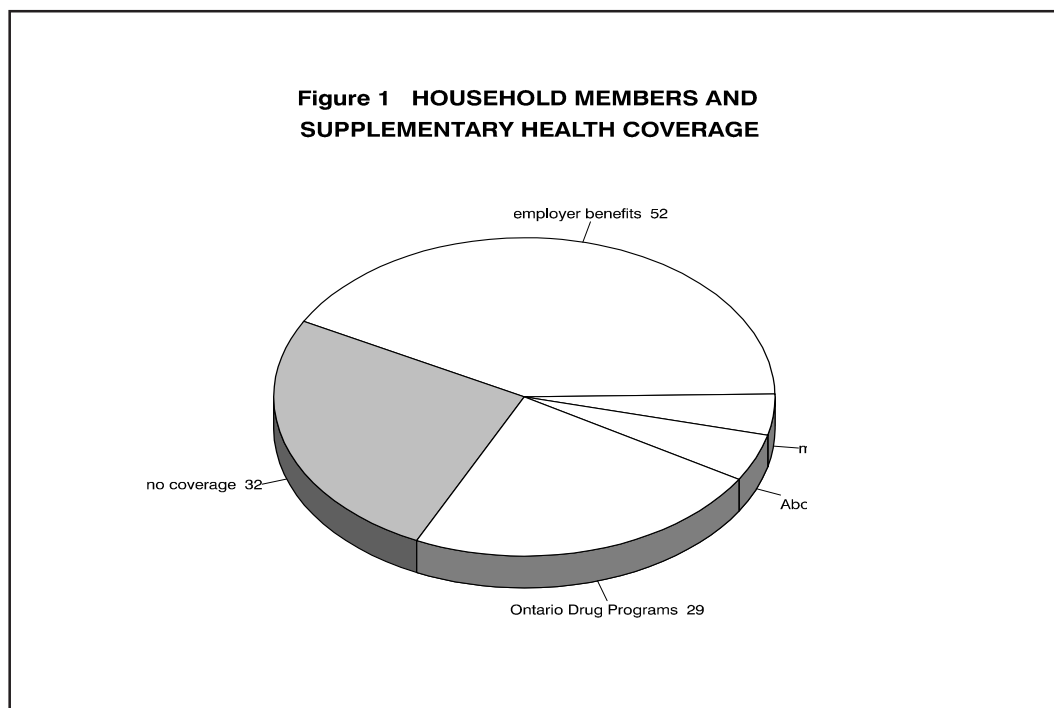
tions. You're up-to-date with all the new technology, you have access to anything and everything that you could possibly need. And on OHIP, you're allowed the bare minimum. If you need anything over and above that bare minimum, good luck because you won't be getting it from OHIP, you'll be paying for it yourself and that scares me. I'm feeling like the bottom's fallen out all of a sudden. We had a really great drug and dental plan. We had semi-private coverage at the hospital. We had all those extras through my ex-husband's insurance. I feel like the rug's been pulled out from under my feet.

Private health insurance acts as a buffer, helping to offset cuts to publicly provided services. The absence of private coverage, according to Veronica, puts her and her children at risk.

Of the 124 participants in this study, 26 percent (32 individuals) had no private health

insurance coverage, and 10 of those 32 were children. In some cases, one member of the household had coverage but did not extend benefits to other members. Some had no coverage because of unemployment, while others had no benefits from their job. Social assistance coverage provides only limited supplementary health benefits (i.e., over and above the medicare services available to all Ontarians).

With the shrinkage of the range of health services provided under medicare, private health insurance tied to particular jobs and relationships is growing in importance. Janet and Christopher have seven children – Janet has four and Christopher three from previous marriages. Three of Janet's children live with them full time and Christopher's two sons are there every other weekend. Their other two children are adults and live independently. Christopher and Janet do not have private health coverage through



Co-Payment For Prescription Drugs

Currently, 1.1 million social assistance recipients and 1.3 million seniors no longer have drugs provided without cost by the Ontario government. Welfare recipients and seniors with individual incomes under \$16,000 a year now have to pay \$2 for each prescription they have filled. Seniors whose individual income is more than \$16,000 a year or whose family income tops \$24,000 a year face a \$100 deductible and have to pay a dispensing fee of up to \$6.11 for each prescription.

their work, but Janet's children have benefits through their father (Janet's ex-husband), while Christopher's sons have no coverage. Of the seven members of this household, only three have access to extended health coverage.

Anne is one of 29 individuals in our study who receive drug benefits through Ontario Drug Programs (covering Ontario Works and Ontario Disability Support Plan recipients, senior citizens and people receiving Trillium funding) and are now required to make co-payments. A single parent in southeastern Ontario, Anne told us in early 1997 that the reduction in social assistance benefits and the introduction of a \$2 co-payment were adversely affecting the health of her children:

I can't afford prescriptions half the time because I have to pay \$2. I don't have \$2. My cheque comes, I buy my groceries, pay my bills. I'm left with maybe \$50. And that supplies me with milk and bread, whatever. And then when your kid gets sick and the prescription's not covered, which in a lot of the cases it is with the asthma medication, you have to borrow the money and you're in debt for the next month. And you worry about writing a postdated cheque for \$2. It's that bad sometimes.

The government's introduction of Ontario Works has reduced access to drug and dental care for social assistance recipients. Dental care for adults in Ontario Works is considered a discretionary benefit through Special Assistance and is limited to emergencies. In some cases, welfare recipients no longer will be able to see the dentist of their choice, but instead will be assigned to a public health dentist named by the municipalities [Hudson 1998b: A7]. Such was the case with Samantha, a full-time student and mother of two infants, whose dentist refused her treatment in light of the new regulations:

I never knew that social assistance changed dental benefits. I made a dentist appointment and brought the stuff that I would normally bring. When I got to the dental office, they told me we can't see you because you're on welfare, you're no longer covered. They rejected me unless I paid 40-something dollars.

Many participants have no dental coverage, and even adults who receive social assistance are eligible only for emergency dental services. Dental health is critical to overall health. For those household members without coverage, the lack of a universal, publicly administered dental health insurance plan comparable to medicare means that most do not seek dental care.

Participants with significant health care needs maintain that changes to the health care sector are giving rise to a need for increased private health insurance as drug costs continued to soar and co-payments are introduced. Rosie and Bob looked into purchasing additional health coverage. Factors such as age and poor health made premiums unaffordable. They explain:

Rosie: Two years ago the insurance company wanted \$500 to get coverage. I'm 60.

Bob: Yeah, but that's for your ordinary person. They're not going to give you a \$500 plan when you spend \$2,000 worth of drugs. That's for somebody who may need a prescription once every two or three months. But if you've got somebody as sick as Rosie spending \$2,000, they're not going to give it to you for \$500 because there's no profit that way.

Even with extended health coverage, through multiple sources such as the Ontario Disability Support Plan and support from organizations such as People With Aids, Richard – who lives with AIDS – talks about incurring health-related expenses ranging from \$50 to \$60 a month:

I'm cutting back on things I need because I can't afford it. A person with HIV and AIDS needs double the protein of a healthy person. I find vitamins are helpful but they're too expensive. They're not covered at all, not a penny. You cannot hand the receipt into the People With Aids Foundation, they won't reimburse you for it. They will try and give you a free bottle of vitamin C or multivitamins but sometimes they haven't got them.

The working poor are also adversely affected by deinsured medicare services and rising out-of-pocket expenses for health care. According to the Canada Health Monitor, which polls Canadians on health care, in 1997 only slightly more than one-third of working people said their employee benefits plans covered all the drugs for the conditions from which they and their families suffered. Others had no benefits or had limited plans. As we argued in *Take It or Leave It: The Ontario Government's Approach to Job Insecurity*, governments have a role to play in alleviating or exacerbating labour market insecurity [Noce and O'Connell 1998]. More and more Canadians lack supplementary health coverage because they work in

nonstandard, casual and part-time jobs that typically provide no benefits.

When we first met Rick, a full-time unionized worker in the transportation industry, in early 1997, he spoke of his employer's reluctance to invest in workers:

The companies would rather hire part-time workers. That way, they don't have to pay benefits.

Randy's experience is similar. He is a part-time mechanic and father of three in a small southwestern Ontario city. His employer does not provide supplementary health insurance. After approaching different insurance companies for family coverage, he concluded that the cost of premiums far outweighs the benefit of less-than-comprehensive private coverage:

But even if we were to pay the \$175 a month for family coverage, it's still only 80 percent, so you still have to come up with another \$50 or \$70 on a \$300 bill. So there's absolutely no way you can get dental care.

The importance of a range of publicly funded health services was highlighted by Randy:

A dental professional comes into the school and checks the kids' teeth. A health nurse comes in and checks for head lice. Someone comes in and listens for speech problems. And that's how we get our kids' health services. We tried to get dental care for two years and couldn't find anything we could afford. A nurse came to the school and this is the only way we can get both of our kids in dental care.

The provincial government funds many public health services and establishes the policies by which some of the services are governed.

Until 1998, Ontario paid 40 percent of public health costs and the municipalities the other 60 percent. In 1998, the province downloaded the full cost of public health to the municipalities. But Ontario then reinstated cost sharing in 1999; as of January 1999, the province and municipalities will share the costs on a 50-50 basis. Planning is difficult under such circumstances. The province also introduced a new screening tool for school-based dental care, which reduced the number of schools required to check the teeth of all students. Michelle recounts how her children were affected:

Up until a couple of months ago, the children had dentists going to the school to check their teeth. The kids brought a letter from the school, saying that they won't be doing that service any more. So it's a major concern.

Currently, there is considerable variability in the groups served, eligibility requirements, level of care and delivery systems across municipalities [Basrur 1999b: 9]. More children will suffer from poor dental health as a result of conditional program guidelines that restrict dental screening in schools.

Some Ontario families and individuals are fortunate to work for employers that provide supplementary health insurance or to be covered by someone whose employer provides such coverage. Those who have limited, supplementary, publicly provided health coverage – social assistance recipients and seniors, for example – are struggling with de-listing and co-payments. Many of those with no access to additional insurance do not seek medical care, in particular dental care, because they cannot afford the cost of dental treatment or prescriptions. Even for those who have some form of supplementary coverage, the fact that patients must pay first out of their pocket and only later receive reimbursement leaves many households with little money to cover their other necessities.

HEALTHY PUBLIC POLICY: THE MANY DIMENSIONS OF HEALTH

Sabrina and Elizabeth, housemates who work in the social service sector, find that cuts implemented in several policy areas by the current Ontario government make it harder for people to stay healthy:

Sabrina: Anything that adds stress to people's life is going to impact on people's wellness. All these cutbacks are affecting people who are already stressed to the max. I don't know how some people even get up every morning.

Elizabeth: It is a domino effect, they cut welfare and then social housing. Nobody can afford to live anywhere.

Sabrina: You can never move from where you are because there is no rent control. Your kids, what kind of an education are they getting? Constant stress from every angle. God forbid you have any health problems that need treatment!

As Sabrina and Elizabeth suggest, the formal health care delivery system is only one determinant of health for Ontarians. According to the 1996 Federal, Provincial and Territorial Advisory Committee on Population Health's *Report on the Health of Canadians*, determinants of health are understood as the many factors that influence the health of individuals and populations, including income, social status, social support networks, education, employment, environmental factors and coping skills. Participants like Amy see health care broadly, encompassing not only the institutional aspects of health care, such as hospitals and doctors, but also as services that enable her and her children to access health care and that promote health and wellness.

Amy's story

Amy lives with her three children in Toronto. When we first met her in 1997, Amy was enrolled in Ontario Basic Skills, an upgrading training program for adult learners. At that time, Amy's household was receiving a welfare top-up, a supplement for working people with very low incomes. In our second interview, Amy told us that she and her husband had decided to separate. Their break-up caused a substantial decline in Amy and her children's income. This drop in income was compounded by changes introduced to social assistance. Under the *Social Assistance Reform Act 1997*, Ontario Works no longer provides assistance to full-time students. In addition to having to incur an Ontario Student Assistance Program (OSAP) debt load of \$16,000, Amy also lost her family's drug and dental coverage. Alternative health coverage available through her college's student plan proved too costly because Amy would have to pay the full cost of medications up front and then wait for reimbursement:

Right now, Lloyd needs to go to the dentist, but when you get off of welfare you lose a lot of things. OSAP doesn't cover this stuff, drugs, dental and all those things. Alain is the lucky one.

Alain, Amy's son who has cerebral palsy, has coverage through the Ontario Disability Support Plan's renamed Assistance for Children with Severe Disabilities (formerly the Handicapped Children's Benefit). Even with such coverage, Amy worries that health-related services are becoming increasingly more difficult for Alain to access:

I'm worried about Alain's health, what's going to happen in the next few years, because the government is cutting everything. He's not even eligible for Wheel-Trans [municipal transport

for persons with disabilities]. They don't consider Alain disabled enough and he has cerebral palsy.

As Amy discovered in trying to secure assistive devices for Alain, there are limits to so-called 'extended' coverage programs. She outlines the dilemma of choosing between a wheelchair and a stroller:

His wheelchair is covered by Assistive Devices, but they cover only the wheelchair. He needs a walker, which I have to pay for. That's \$200. He needs night-splints to stretch his knees, but Assistive Devices won't cover them. They don't consider it necessary. That costs \$400, and it's going to have to come out of my pocket. He needs a stroller, he's outgrown the one I have. The stroller is \$2,000 because it's customized especially for him. You have two choices. You get the wheelchair or the stroller. He needs the wheelchair for transportation, but on the bus, he needs the stroller. I have to either get one second-hand or save to the year 3000 to buy it.

Amy also spoke of housing as integral to the health of her family. During our first interview in 1997, Amy was concerned about her overcrowded and less than adequate living conditions. Her inability to secure Alain a walker through the Assistive Devices Program forced him to crawl around their apartment that was infested with cockroaches: "*I want to move, but I can't find a good, suitable place where my kids can be okay and I don't have to worry about Alain crawling on the ground and picking up cockroaches.*" Concerns over neighbourhood safety and a rent increase resulted in Amy's moving in 1998. Although Amy reports feeling more satisfied with her new location, in early 1999 a pending rent increase has her thinking of moving once again. Since 1998, Amy has been on a waiting list for subsidized housing in Toronto:

Social housing wants to send me all the way to Scarborough. I'm not moving to Scarborough: My school is downtown, Sick Kids [hospital] is downtown, everything is downtown and I don't drive. The worker said that I'm not going to be coming to Sick Kids all the time. How does she know that? I have a disabled child. In August, Alain had a seizure that lasted for two hours. So he was in the hospital for one week, in intensive care for two days. Of course I need to be near my child's hospital.

Amy confides that because her rent is more than she can afford, she often finds herself cutting back on food to manage other household expenses: “*Sometimes the children miss a meal. It's not all the time I cook healthy. To cook healthy, a meal with vegetables, is expensive.*” Her concern for the well-being of her children prompted her to go to her doctor to get a prescription for a nutritional supplement: “*I went to the doctor to get Ensure for Alain and the doctor told me he couldn't prescribe it for me because Alain is not malnourished.*” She goes on to say: “*If anything happens to him, they will say I'm a bad mother, I didn't take care of him. Something is wrong here.*” Inadequate money and community support make parenting more difficult. Amy feels as though her fitness as a mother is being called into question.

The health care sector does not act alone in ensuring good health. The ways in which Amy's household and Ontarians more generally experience changes in the health care sector are influenced by cuts in other social programs that affect well-being. When asked what Ontarians required to be healthy, participants cited safe, affordable public transit, housing, improvements in water and air quality, and accessible and effective public health services. While health care funding in some areas is now increasing, it comes at the cost of other services that allow people to be healthy.

Housing

Jenny, who lives in subsidized housing in southeastern Ontario with her three children, speaks of her difficulty in finding affordable housing:

There needs to be a lot more affordable housing out there because there's a lot of people out on the streets. Not knowing whether you can afford to live in your place one month to the next, that's going to cause a lot of stress and strain on a family. And all that strain, it comes out sooner or later. It's going to come out somewhere.

The dwindling supply of low-cost rental units, along with the withdrawal of support by both the federal and provincial governments for new social housing programs, have made affordable housing much harder to find in Ontario. Changes in rent control that lift the rental ceiling when a unit is vacated and the reduction in social assistance's shelter allowance have left low-income households with fewer housing options. According to the Ontario Non-Profit Housing Association, in March of 1999, almost half of all tenant households in Ontario faced affordability problems and almost one in every four tenant households was at risk of homelessness [1999]. As of June 1998, in Toronto alone, 40,000 households numbering 100,000 people were on a waiting list for social housing.

Participants with precarious housing speak of living in overcrowded and substandard conditions. The stress of inadequate living conditions leads some participants to comment on the negative impact this problem has on their health. Sadan, who lives in subsidized housing in the Greater Toronto Area with her four children, talks about how, in the process of securing safe and affordable housing for her family, she gave up many ethno-racial supports and community contacts:

In my old neighbourhood, if I didn't have food I would go to a community agency and they would give me a food voucher, so I could buy milk and cereal, or I would go to a friend's and borrow money. In this area, I don't know anybody and everything is far away. It is a nice place, it's quiet, no violence, but I don't know where the food bank is, where to volunteer – there is nobody.

Having to move around often in search of suitable and affordable housing disrupts social networks and opportunities for social interaction, all of which can have an impact on health [Federal, Provincial and Territorial Advisory Committee on Population Health 1996].

Antonio's family, in Toronto, is one of an increasing number of Ontario households now spending more than 30 percent of total income on housing. Antonio explains that he spends less on food in order to pay rent: *"There isn't enough money to cover a good diet. We buy what we can but there isn't a regular basic diet. We lack proper nourishment."*

The group of tenant households spending more than 30 percent of their income on rent has increased dramatically from 33 percent of all tenant households in 1991 to almost 45 percent in 1996. In 1996, close to 213,000 households in Toronto alone were paying more than 30 percent of their income on rent, and more than 106,000 households paid more than 50 percent [Mayor's Homelessness Action Task Force 1999: 137]. Antonio's experience shows that if the cost of housing consumes too much of available income, other needs suffer and people face difficult choices about how to allocate their remaining income – all factors that contribute to stress and affect health.

Nutrition

Teresa, a low-income woman with chronic health problems, requires a special diet. Social assistance changes have made it increasingly difficult to get the basic dietary requirements that are essential to her health: *"I have a special needs diet, but it's not being met because I'm getting all the assistance that I can."* Teresa is referring to the change in the Special Diet Benefit. Under the newly created Ontario Disability Support Plan, there is now a cap of \$250 per month on the Special Diet Benefit [Ontario Ministry of Community and Social Services 1998: 15]. She explains the kinds of choices she is forced to make:

You're supposed to have three meals a day, and I go sometimes two, three days without eating. And even if I use the food bank, they can't provide me with the types of food that I need. They try, but it's difficult for them because they only have so much to work with. So I'll go without eating for a couple of days, or I'll eat just one meal a day.

Many low-income households are turning to food banks to supplement their diets. Jenny describes her experience:

I won't even go to the City food bank anymore because every time we've been there, we get sick. We'd all get stomach cramps; we'd be throwing up and I'm convinced it's the food. I'm not trying to knock it because it is a good thing. We do need it in this community, but the building that it's in is so filthy. I'm sure there are cockroaches in it. It is old and grungy and it smells like mould when you go in there. Half the food they give you is not fit for consumption.

Having to rely on a food bank often does mean compromising the quality and freshness of food. While not everyone's experience is as severe as Jenny's, a 1998 study of women and children using Toronto food banks found inadequate intakes of iron, magnesium, vitamin A, folate, protein, zinc and calcium – nutrients that affect prenatal and infant health and child development, and increase the risk of chronic disease [Basrur 1999a: 4].

For Jenny, who is pregnant, getting quality food has been made even harder because the allowance paid to expectant mothers receiving social assistance has been cut, and her municipality did not pick up the cost. She is now forced to look for additional supports in her community for such things as milk and prenatal vitamins:

I'm finding that it's a lot harder now because I'm pregnant and I know I'm supposed to be drinking a lot milk and eating really healthy. When I was not pregnant, I could go without food. I've done a lot of research and there is a place that I've been accessing that is a godsend. They have a food cupboard so I can go there every Friday. They give you information on pregnancy, answer questions and you can talk to other moms. They also give a \$10 food voucher every week, so at least I know I'm going to have a bag of milk in the house.

Until recently, Ashley lived in Toronto with her daughter and granddaughter. She told us how changes in social assistance made it increasingly difficult to meet basic dietary requirements:

Sometimes it's better for my granddaughter to go to day care because I don't have much food. I can't give her a balanced meal. I can go without, but she needs to have something. I make sure that when she leaves day care, that they

fill her bottle up with juice so that she has something to bring home.

Transportation

Julie's biggest challenge in securing the health care she needs revolves around issues of transportation: "If you don't have transportation that's flexible and responsive, then you're less likely to go and access services." Recent changes to municipally provided transit for persons with disabilities have made services less flexible and responsive.

Teresa, who has multiple health and mobility problems, explains the impact on her:

With the cutbacks, Wheel-Trans decided that they weren't going to let people with heart and lung conditions use it. I have a lung disease, which was why I had Wheel-Trans, plus I have a lot of other internal organ damage, severe osteoporosis and arthritis; but it still didn't qualify me to use Wheel-Trans. I couldn't climb three stairs and I couldn't walk 75 meters. But without Wheel-Trans, it's either TTC [Toronto Transit Commission, the area's public transport] or stay home. I can only use the TTC if it happens to be one of those stations that actually has an elevator that works, or a working escalator: Half the time the escalators aren't working. Or there are maybe four subway stops that have an elevator and then you have to transfer to a bus anyway. I can't use the TTC system, it's too difficult.

In Toronto, a revised application and eligibility process was accompanied by a punitive policy designed to suspend or cut service from users who were no-shows or did not give enough advance notice of a cancellation. These changes, largely the result of provincial downloading and loss of a \$31 million Toronto Transit Commis-

sion subsidy, sought to reduce the number of users at a time when Metro Toronto's Transit Accessibility Needs Study forecast a two percent annual increase in Wheel-Trans demand. The cutbacks to this essential service in Toronto – and others across the province – have become a barrier to accessing health care for those with disabilities.

Jackie lives in southeastern Ontario. She has been trying to secure transportation services for her daughter who has a mobility impairment. She discovered that tightened eligibility requirements make it harder for her daughter to qualify for transportation services. Such restrictive policies influence a host of other interdependent services contingent on such a definition of disability:

To be disabled, you can't walk from here to there, but my daughter can't walk from here to the corner store. So what's the difference? There's nothing in between. You've got to be in a wheelchair. I'm glad that there are services for people with disabilities, but the definitions of disability are too rigid. What's there for those in between?

Income

Even for those who are able to meet basic needs through visits to food banks and assistance from government, agencies or friends, there are strong health risks associated with low incomes. Rosa, a single mother who recently found full-time employment and no longer receives Ontario Works, talks about the stress of being poor:

Sometimes I feel like I am going to explode. I'm walking around with ten cents in my pocket. I'm trying to hold myself together. It's so hard. I feel so helpless.

Pam, who lives in a northern Ontario city, explains:

When there's not enough money to survive, to live a healthy lifestyle, you change the definition of stress. Stress moves from "I can't replace my refrigerator" to "I can't take my kid to the hospital or to the doctor because I can't afford a taxi." So stress becomes \$5 instead of \$500.

According to the *Report on the Health of Canadians*, better incomes are related to better health [Federal, Provincial and Territorial Advisory Committee on Population Health 1996]. Higher incomes enable people to purchase adequate housing, food and other basic necessities. Higher incomes also mean more choices and afford people more control over their lives.

Governments have a crucial role to play in making social policy and spending decisions that should consider the broad range of varied health needs of the population. The downloading and restructuring of health care are being accompanied by deep cuts in other programs and services. These cuts are not just cumulative but mutually reinforcing.

CONCLUSION

The Ontario households in our study understand that health care reform is about more than just hospital restructuring: It also is about reforming their expectations regarding the government's role in funding and delivering health services. From premature discharge from hospital to the lack of services and entitlements in long-term care to lengthening waiting lists for specialists, participants tell us again and again that the reforms undertaken by the provincial

government are driven more by cost cutting than providing quality care. In its April 1999 *Speech From The Throne*, the provincial government asserted that it was “preserving a public health care system on which every family in Ontario can rely.” This assertion seems contrary to the experiences of the 40 households that have been talking with us over the course of two years. Instead of the “universally accessible health care system” promised by the Ontario government, household members say that new policies shift responsibility for health care onto individuals and families and are based increasingly on one’s ability to pay rather than the need for care.

Household members assert that staying healthy requires more than an excellent health care system. From social assistance to transportation services, they tell us that the policies of the provincial government – cumulatively – are making it harder and harder for Ontarians to be well. Increased spending on health care cannot make up for the negative effects on people’s health that dramatic social spending cuts have had in Ontario over the last four years. It appears that the increases in health care funding announced in Ontario’s 1999 Budget will be financed by deeper cuts in almost every other area of public life.

Endnotes

1. Figures are for operating expenditures only and do not include capital expenditures. 1997-98 and 1998-99 figures are adjusted for restructuring expenditures and reimbursements from municipalities (\$154 and \$529 million and \$52 and \$206 million, respectively) and in 1998/99 for Year 2000 spending (\$287.5 million).

2. Total bed figures count acute, rehabilitation and chronic beds, including mental health beds. Figures do not include beds in nursing homes or homes for the aged.

3. Because hospitals like Wellesley Hospital are unique in Ontario, we have chosen to identify them. The household members cited consented to having these identified.

4. In April 1999, the Ministry of Health announced that long-term care centres would be built on four former hospital sites. The centres should be able to accommodate individuals who require chronic care levels of care. The measure forms part of the 1998 long-term care announcement indicating that 20,000 new beds will be created in Ontario over the next eight (now six) years. The initiative responds in part to the growing problem of increasingly ill people being placed in nursing homes or homes for the aged who should be in chronic care facilities, which have seen bed closures. While these beds are needed, the catch-up response is indicative of poor planning across health care sectors.

5. Long-term care beds include those in nursing homes and homes for the aged as well as those in acute and chronic care hospitals occupied by long-term care patients.

6. According to the Provincial Auditor's report for 1998: "research into the cost-effectiveness of long-term care community services could help the Ministry (of Health) make decisions regarding health care practices that reduce costs while improving or maintaining the quality of care... Comparing the costs of long-term care community services with institutional care requires good information about the actual costs of those services. At the time of our audit, the Ministry did not have systems in place to provide this information" [1998: 107].

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Appendix B

Hospital Closures, Bed Losses and Funding Cuts In Ontario¹

Belleville and area

- Four hospitals to amalgamate
- \$8 million (9%) being cut
- 105 beds cut to date, all will be re-added by 2003

Brant County (Brantford)

- One hospital to close
- \$16 million (20%) cut
- 94 beds closed already, another 29 by 2003, a 26% total reduction in beds

Brockville

- Psychiatric hospital to close, services decentralized and management to Ottawa
- Two hospitals remain open; one hospital will provide only continuing care and rehabilitation services
- \$5 million (14%) cut
- 40 beds closed already, another 22 will close by 2003, a 24% total reduction; plus all 295 long-term mental health beds are closing

Chatham and Kent County

- One hospital to close
- One emergency department closed in 1996
- Up to \$12 million (18%) to be cut
- 59 beds closed already, 42 to be added by 2003, for a total loss of 5% of beds

Cornwall and surrounding area

- At least 1 emergency room (Hotel Dieu) will close
- \$9 million cut (15%)
- 168 beds closed (27%), 78 to be re-added by 2003 (total reduction of 15%)

Essex County (Windsor)

- One hospital site to close
- Two emergency departments (of 4) to close
- \$33 million cut (14%)
- 257 beds closed to 1999, 154 to be added by 2003, a 9% total reduction in beds

Greater Toronto Area (GTA) excluding Toronto

- A number of hospitals amalgamated
- One hospital to close
- One emergency department closed
- \$82 million cut
- 628 beds to be added by 2003, 21% increase in beds

Hamilton

- Two of seven hospitals to close
- One hospital emergency department of five to close
- \$100 million (17%) cut
- 265 beds closed to date, a further 177 to be closed by 2003, for a total reduction in beds of 19%

Kingston and area

- Three of six hospitals closing
- One hospital reduced emergency to 14 hours daily
- \$58 million (26%) cut
- 236 beds closed and another 80 beds closing by 2003, a 28% reduction in beds

London-St. Thomas

- Both psychiatric hospitals to close and a smaller forensic psychiatric health centre to be built
- Two other hospital sites to be closed
- Two emergency departments to close
- \$46 million (9%) to be cut
- At least 567 beds (25%) to be lost by 2003

North Bay

- Three hospitals/sites to close, new acute care hospital to be built
- One emergency department (St. Joseph's) closed
- \$7 million (13%) to be cut
- 222 beds to be closed in total (29%)

Ottawa

- Two hospitals to close
- Montfort, the city's only French language hospital, will have a reduced role, mainly providing ambulatory care
- At least one emergency department closing
- Other hospitals will amalgamate or become subsidiaries of existing hospitals
- \$100 million (14%) cut from hospital budget
- 688 beds closed in total by 2003 (23% reduction)

Parry Sound

- Two hospital sites to close and new hospital to be built
- \$2 million cut
- 64 beds (48%) to be closed in total by 2003

Pembroke

- One of two hospitals closed
- One emergency department closed
- \$10 million (27%) of budget cut
- 50 beds to be closed by 2003 (25% reduction)

Peterborough, Cobourg, Port Hope, Haliburton, Lindsay, Campbellford

- Two hospitals and two private hospitals to close
- Two emergency departments (one in Peterborough and one in Port Hope) to close
- \$28 million (18%) cut
- 64 beds closed so far, 27 beds will be added by 2003, a 4% reduction in total

Sarnia and area

- One of three hospital to close
- One emergency department to close; one to move to 18 hour/day urgent care
- \$19 million (19%) cut
- 112 beds closing (25% reduction)

St. Catharines & Niagara Region

- Seven hospitals amalgamating
- One private hospital closing; one hospital will have significantly changed role
- One hospital closing emergency department and creating urgent care centre
- \$30 million cut (12%)
- 252 of 1,393 beds closed by 1999, 118 being re-added by 2003 (total reduction of 10%)

Sault Ste. Marie

- One hospital to discontinue most services
- One emergency department closed (Plummer)
- \$5 million cut (6%)
- 53 beds cut to date, a further 29 by 2003 (total reduction of 27%)

Sudbury

- Two sites closing when the three hospitals amalgamate
- Two emergency departments closing, only one hospital provides emergency services
- \$41 million being cut
- The number of beds is dropping from 751 to 554 by 1999 (a reduction of 26%), 106 being re-added by 2003 (total reduction of 12%)

Toronto

- 11 hospitals to close in total: one hospital closed (doctors), 10 more still to close
- 14 hospitals amalgamating into five
- One emergency room closed (doctors), one with reduced hours; 12 more to close or change hours
- \$470 million cut (18% reduction)
- 1,332 beds closed by 1999, another 63 to close by 2003, for a total reduction of 13%

Thunder Bay

- Three of five hospitals to close
- Two emergency departments closing; all emergency services will be provided at one hospital
- Acute care will be provided at a single site
- \$40 million to be cut
- 317 beds closing in total by 2003 (33% reduction)

Waterloo

- \$46 million cut (21%)
- 150 beds already closed, another 158 beds to be closed and then re-added by 2003 (total reduction of 13%)

1. Information is provided for each of 22 urban regions identified by the Health Services Restructuring Commission.

Source: Compiled from information provided by the Health Services Restructuring Commission (1998a,b; 1999a, b, c), the Ontario Hospital Association (1999b), the Ontario Medical Association (1998) and specific hospitals.

Reports available from the *Speaking Out* Project

Project Description: Research Strategy and Methodology
December 1997

Periodic Report #1
Take It or Leave It: The Ontario Government's Approach to Job Insecurity
January 1998

Periodic Report #2
Act in Haste...The Style, Scope and Speed of Change in Ontario
January 1998

Periodic Report #3
Centralizing Power, Decentralizing Blame: What Ontarians Say About Education Reform
October 1998

Periodic Report #4
Costs, Closures and Confusion: People in Ontario Talk About Health Care
May 1999