Manufacturing Social Exclusion in the Home Care Market

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This paper examines how the health care perspective which dominates home care obscures the broader processes of social exclusion that play out in this arena of public policy. A study of elderly women and women with disabilities receiving home care in Ontario reveals how managed community care generates and reinforces service users’ social isolation and their spatial, institutional, and political exclusion. Analysis of study participants’ experiences points to the challenges of moving away from a market discourse and a health framework to develop home care policy which achieves the inclusion and participation of elderly citizens and citizens with disabilities in need of assistance at home.

Home care, previously a small and rather marginal arena of social policy, is becoming the focus of unaccustomed attention in Canada. Cuts to the hospital and institutional sectors have shifted the site of care to people’s homes. This shift is driven both by economic objectives and by political commitments to smaller government, individualism, and the transfer of work from paid to unpaid contexts (Armstrong and Armstrong 1996; Glazer 1993). Acutely ill people needing short-term treatment and care have joined frail elderly people and people with chronic illnesses and disabilities who now rely on home care services (groups who are the focus of concern in this paper). At the same time, home care is being rapidly reorganized on market-modeled lines: public provision of care is dwindling while...
the roles of the informal, voluntary, and private sectors are expanding (Neysmith 1998). While provinces’ approaches to establishing such mixed economies are influenced by their particular politics and histories, they are all driven by Canada’s responses to the forces of global economic restructuring that are “hollowing out” western welfare states (Jessop 1993, p.7).

Public policy discussions of home, or community, care are located almost exclusively within a health care framework. They focus, typically, on questions of health care funding, supply, and organization and suggest that adequate care at home can be accomplished by, for example, the diversion of more health care dollars from the hospital sector, more efficient management, more precise targeting of services, and better measurement of health outcomes (e.g., British Columbia Royal Commission 1991; Health Service Utilization Task Force 1994; Health Services Utilization and Research Commission Saskatchewan 2000; Sears et al. 1999). The dominating gaze of medicine in the health care arena positions users of home care as patients/consumers/clients with impairments that limit normal functioning. Different issues are highlighted by advocates, labour organizations, and concerned citizens. They argue, for example, for bringing home care under the terms of the Canada Health Act as a universal entitlement, for changing the insecure working conditions of the home care labour force, and for properly recognizing the contributions of family caregivers (Anderson and Parent 1999; CUPE 2000; Morris et al. 1999).

Finally, seniors and disability groups press for change in the marginalized positioning of their constituencies: for their involvement in home care policy-making and delivery, and for services that facilitate not only their minimal maintenance at home but their full participation in social and community life (Barnes 1999; Care Watch Phoneline 1999; Masuda 1998; Meade 1999). In short, they demand to be positioned as citizens, not just as service users.

This paper takes up these groups’ critiques of the confined way in which home care is articulated and examines their claims in terms of the dynamics of social exclusion. To explore the specifics of how social exclusion is manufactured in the context of a burgeoning home care market, we build upon the accounts of a sample of elderly women and women with disabilities currently using home care in Ontario. It is argued that the health care perspective that dominates home care policy obscures the processes of social exclusion that are being played out in this area of social policy: an area that affects not only a large number of Canadians as service users but also large numbers of formal and informal care providers.

“Social exclusion” is seen as the consequence of economic globalization and the resulting restructuring and withering of postwar welfare states. It offers a way of understanding the patterns of marginalization that these massive changes have generated. Social exclusion is conceptualized as a process and thus draws attention to the dynamics rather than the static determinism of social structures:

Social exclusion focusses on relational issues: in other words inadequate social participation, lack of social integration and lack of power. Social exclusion is the process of becoming detached from the organizations and communities of which society is composed and from the rights and obligations that they embody (Room 1995, p. 243).

Importantly, too, exclusion is articulated as a multi-dimensional phenomenon. Synthesizing others’ work on the “plurality” of exclusionary processes, Littlewood and Herkommer (1999) identify, for example, the economic, cultural, spatial, and political dimensions of social exclusion and call attention to their cumulative consequences.

In a review of the literature in this area, Jenson (1998) places discussions of social exclusion within larger debates about social cohesion and its contested conceptualization. She sounds a cautionary reminder that, historically and currently, social
cohesion often foregrounds social order, rather than social justice or social equality. Specifically, many of its proponents reflect a tradition in which visions of community are explained in terms of shared values rather than competing interests, in which consensus rather than conflict is assumed and in which social practices rather than political action are emphasized (ibid., p. vii). Jenson’s detailed mapping of Canadian work on social cohesion reveals that debates tend to focus at either the local or national level, seldom both. Research at the local level emphasizes issues of belonging that result from participation. Discussions at the level of federal, provincial or pan-Canadian organizations such as the Canadian Labour Congress or think-tanks such as the Caledon Institute of Social Policy, as well as in more traditional academic contexts, emphasize citizenship, national identity and multiculturalism (ibid., pp. 19-20). This paper aims to make links between these levels: between dominant discourses on citizenship, the design of home care programs, and the local experiences of those who use them.

A primary application of the idea of social exclusion has been to the multidimensional processes that are generating new forms of poverty, lack of access to employment and the physical segregation of marginalized populations in urban areas (Byrne 1999; Madanipour, Cars and Allen 1998). It has illuminated, in particular, how such groups as unemployed youth or underemployed immigrant populations are pushed to the social margins. In like manner, it can be usefully applied to show the exclusionary processes faced by elderly people and people with disabilities in need of assistance at home.

The tension for these populations between exclusion and inclusion — between confinement at home and participation in society — certainly predates the current restructuring of state social provision and visions of social inclusion resulting from efforts to promote so-called “caring communities.” The literature on community-care policies is replete with analyses of their rhetorical success and, commonly, their practical failure. “Community” proves to be a seductive euphemism obscuring isolation and lack of integration. “Care” proves to be an undervalued and highly gendered activity assumed largely by families and, when publicly undertaken, under-funded and limited to the maintenance of basic functioning rather than to enabling autonomy and participation (Barnes 1997; Neysmith 1998). The marginalization of the recipients of such limited forms of community care is deepened by neoliberal conceptions of citizenship that prize self-sufficiency and independence, disparage need and dependence and, thus, permit receding state intervention and greater privatization of care:

“Normal” citizens are ... first and foremost constructed as individual participants in the labour market. This individual is supposed to translate his/her needs for care in terms of market-oriented behaviour, thus conceiving him/herself as a care consumer in a market of supply and demand of caring services (Sevenhuijsen 1997, p. 57).

These ideological and political developments are easily discernible in the Canadian context as public responsibility for welfare and social security is sloughed off and a discourse of individual responsibility is embraced. Accordingly, the federal government has chosen not to act on recommendations that a national home care program be developed (National Forum on Health 1997); such a program would have assured access to care at home as a universal entitlement. Instead, home care continues to be an unmandated arena of provincial jurisdiction and — for provincial Ministries of Health — has been the focus of quests for containment and off-loading. Citizens who are elderly or live with chronic disabilities find themselves positioned as consumers in straitened provincial home care marketplaces. Positioned in this fashion in the context of public health care and in a wider cultural context that de-values their old age and disability, it is unsurprising that they become easily “detached” and excluded from communities and identities beyond the confines of their households and their impairments (Barnes 1997).
The Ontario case is illustrative of these developments and it is where the study reported here was carried out. Like other provinces, Ontario developed a system (albeit poorly coordinated) of home care in the 1960s and 1970s through cost-sharing initiatives under the Canada Assistance Plan. Through the 1990s, it faced increased demand and its already fragile resource base was further weakened by the combined effects of block-funding, cuts in federal transfer payments, and provincial governments’ efforts to reduce deficits (Armstrong and Armstrong 1999). In 1996, the newly elected Conservative government introduced a system of “managed competition” in home care, seeking to reduce public costs and enhance efficiency and consumer choice (Williams et al. 1999). The role of the public sector is confined to assessment and the contracting-out of service provision to competing non-profit and for-profit home care providers — activities undertaken in 43 Community Care Access Centres (CCACs) distributed throughout the province. Case managers in these centres are charged with assessing and monitoring people’s eligibility for services, with arranging individual packages of care through the various providing companies with which their CCACs have contracts, and with linking them with other arenas of the mixed economy of care (informal supports, private pay services, volunteer organizations, community resources, etc.). The language of “managed competition” is market-oriented; service users are sometimes “clients” but, more often, “consumers” or “customers.” With rising demand and capped and uncertain budgets, the CCACs have rationed their services stringently (Government of Ontario 1999).

This service model, case management coupled with a discourse of scarce resources, operationalizes community care very narrowly. Eligibility regulations accord priority to medical needs and basic bodily maintenance; no room is left for more spacious or inclusive responses to the needs and aspirations of frail elderly people or people with disabilities. Critical of comparable approaches to community care in the United Kingdom, Barnes notes that:

If this (community care) is to be successful then it has to involve rather more than the production of individualized care packages, based on professional assessments of need. It has to involve enabling people to participate in decision-making processes about services, and in social, economic and political life more broadly (Barnes 1997, p. 172).

Little is known of the impacts on home care users of the narrowly managed model that now dominates service delivery or of the less-visible economic, political, and cultural processes in which home care is embedded. In what Schram (1995, p. 40) terms a “bottom up” approach to research that recognizes service users as knowledgeable participants in the public policy process, we explore the standpoints in this shifting political context of service users who are living with long-term disability or illness.

**Methodology**

To understand the realities for frail elderly citizens and citizens with disabilities of their positioning in the mixed economy of home care, the research reported here takes a qualitative and longitudinal approach: qualitative in order to give primacy to individuals’ articulation of their experiences and concerns, and longitudinal (1998–2001) in order to track changes in their health and social situations and in the shifting political and home care environment. The study focuses exclusively on women’s experiences of home care receipt: especially at more advanced ages, women make up the majority of home care users (Wilkins and Park 1998), and gendered assumptions about dependency, bodily frailty and citizenship generate particular jeopardies for women.

A purposive sample (Mason 1996) of women relying on home care in an ongoing fashion was recruited through the newsletters of three community-
based advocacy organizations concerned with the well-being of older people, by word of mouth through their memberships, and through a number of related community groups concerned with long-term illness and disability. Participants were located through community ties rather than service organizations so that the research and the researcher were clearly not associated with services or providers on whom women relied. In recruiting sample members, a range of experience was sought in terms of health status, length of service receipt, social class, culture, and marital and family status. A preponderance of older women was sought in light of the particular significance of home care for this age group.

The sample of 27 women now taking part in the study range in age between 35 and 96; 20 are over 65. Participants live in their own homes either alone (20) or with others (7). They are all located in urban southern Ontario and fall into the catchment areas of seven CCACs. They live with a variety of chronic conditions and disabilities (e.g., arthritis, osteoporosis, fibromyalgia, depression, multiple sclerosis, cerebral palsy, the consequences of strokes and accidents, heart conditions, neurological disorders, breast cancer, polio). Many have multiple health problems. The practical limitations and challenges resulting from these conditions vary and generate a range of needs for assistance: 7 rely on wheelchairs and others’ support with moving so they need assistance twice or more a day; 5 require help once a day; 14 need regular but not daily assistance and one manages with only occasional help. The length of their acquaintance with some form of care at home ranges from 2 to 25 years.

Participants’ family and informal networks vary widely in terms of geographical proximity, availability and emotional closeness. In terms of income: 11 depend entirely on government transfers so live close to Statistics Canada’s low income cut-offs; 16 have some discretionary income as a result of long working lives or the benefit of husbands’ pensions, insurance or ongoing incomes; and 3 have some earned income, one from a full-time salaried job and 2 from sporadic contract work. All participants are white; 19 were born in Canada, 8 came here as immigrants and, for 5 English is not a first language. The transferability of this sample of experience requires some qualification in terms of its narrow range of cultural diversity and its confinement to urban areas and to Ontario (Lincoln and Guba 1985). However, in the tradition of critical ethnography, it provides a rich point of entry for understanding the realities of those who rely on rationed and market-modelled care at home over the long term.

Participants take part in individual interviews with the first author twice a year and at additional points when their circumstances change in some way. At the time of writing (almost two years into the three-year project), most have been interviewed four times. In semi-structured interviews, women are invited to reflect on their health and social situations and on the services and assistance they receive at home — effectively to describe how they understand and experience all sectors of the mixed economy in home care and how they are feeling about their situations, their futures, and themselves. In second and later interviews, changes and developments in all these areas are explored and elaborated. With participants’ permission, interviews are taped and transcribed. In addition, a written record of phone conversations and field observations is kept.

Analysis of transcriptions and field notes reveals patterns and themes in participants’ experiences that have significance for understanding how the impacts of reorganization, funding constraints, and the turn to the market in home care result in a cumulative process of social exclusion.

**Findings**

As study participants reflect on their needs, their supports, and their aspirations in interviews, they
describe the wide landscape of social relations in which they are situated: families, friends, community associations (e.g., social, cultural, spiritual, political), public institutions and services (e.g., CCACs, health and social services, housing authorities, transit systems), programs concerned with assistive devices and technology, drug programs, paid workplaces, and the private market (e.g., commercial providers of home care, therapeutic services, insurance companies and an array of services purchased in the informal economy). Because of their needs for assistance at home, the elements of this relational landscape that can afford support and resources (families, public and private services) are particularly critical to them. In describing these relationships, participants communicate a pervasive sense of tension, as if they engage on an uncertain footing, unsure of their claims and their welcome. An elderly participant articulated this sense of uncertainty and precariousness by saying: “I’m living on the edge.” She was alluding not only to her fragile health but also to the fragility of the arrangements that sustained her at home. She had few family ties, her circle of friends and peers was shrinking, and the home care providers she relied on were proving either undependable or unaffordable. She felt increasingly confined at home, missed engaging in the interests and networks of a lifetime and feared for the future.

In this paper, we explore this process of being disengaged and “living on the edge” using some of the dimensions of social exclusion conceptualized by Littlewood and Herkommer (1999), specifically: exclusion by isolation, spatial exclusion, institutional exclusion, and cultural and political exclusion. Illuminating the interrelated processes that push home care users to the edge will not only broaden understanding of their positioning, but also expand public policy discussions that are, presently, couched in a limiting health care vocabulary that confines attention to the perspectives of health care institutions.

Exclusion by Isolation
Many participants described small and dwindling social orbits and a sense of isolation: “My world’s become very small,” “I’m losing people.” In their articulation of exclusion by isolation, Littlewood and Herkommer note that it is “manifested by the restriction and circumscription of social contact, social relationships and group identity” (1999, p. 15).

When participants’ physical limitations were combined with lack of available transportation, their links with friends and associates became hard to sustain. One regretted, for example, that she could no longer socialize with a group of former colleagues because subsidized transit in her municipality was provided only for medical appointments or paid work commitments during the day and, by evening, she was too tired to venture out. Another woman had given up attending a writing group which she had long valued: the combined constraints imposed by the long waiting times for assisted transit and the lack of an accessible toilet at her destination put it out of her range. Such experiences bring into focus the social impacts of restricted transportation policies and inaccessible environments.

Several participants noted how their ties in their neighbourhoods were shrinking. In the past, they had been used to having their homemakers accompany them to local shops or the bank or take them for short walks, excursions they enjoyed and which sustained for them a sense of local connection and belonging. With CCACs’ cuts to those services deemed inessential — i.e., not medically necessary or concerned with minimal personal care or household help — social contacts were more circumscribed. As one woman observed: “No one really knows I’m still here, that I’m still alive, they never see me out.” Thus, program regulations reinforce rather than reduce isolation.

When involved and available, family members provided social contacts and some were a significant source of practical support. The nature of such contact was often not easy, however. Typically of many older participants, one lamented the limited nature of her contacts with her daughter who held down two part-time jobs and looked after an adult
child with a disability: “She’s tired and has her own troubles ... it’s easier for her just to do my shopping, not take me with her. I understand that. I wish I could just see them in a nice social way, not like this. I’m just another burden.” A younger participant who sometimes relied on her mother when her formal care providers proved unreliable expressed a similar reserve and caution: “She’s old herself now; she can’t be running up and down for me. It’s not right.” These observations suggest, as has other research (e.g., Daatland 1994; Neysmith 1998), that family care cannot simply be taken for granted and used to justify reduced public provision.

While women’s social contacts outside their homes were often circumscribed by dwindling ties, physical constraints, barriers to access and public service rationing, they were circumscribed, too, by their sense of apprehension and discomfort about receiving visitors into their homes. Especially in first interviews which involved for participants the entrance of a stranger/guest, this discomfort emerged in apologies for “untidy” homes or “unkempt” appearances.

Many worried that their homes were not suitable for visitors to see. “I can’t have anyone here; look at the place. I’d be so ashamed.” This reference to poor housekeeping was expressed with particular feeling by many of the older women. In their rationing of services, CCACs have reduced homemakers’ hours and cut out most cleaning, cooking, and household work. Several women felt that they were themselves not presentable enough to have company, that the minimal help they had with bathing (most were allotted a bath or shower once a week), looking after their hair and their clothes meant that they had had to “let things go.” They also felt unable to respond properly to guests: “I can’t be a proper host; I can’t get anything in or give them a meal.” This woman relied on meals on wheels for lunches and a very confined repertoire of breakfast cereal and sandwiches at other times. Lack of appropriate food or drink or the ability to offer it to guests troubled her. Another felt that her failing eyesight and dwindling capacity to cook (“my last claim to fame”) meant that she would soon have nothing to offer and would therefore be even more cut off from others. Such expressions of social reticence and shame reveal how minimalist supports can exacerbate home care users’ isolation by stripping them of central elements of their social selves: their ability to present a socially acceptable appearance and home and to offer refreshment to guests (Howarth 1993).

In the past, home care workers’ presence in the homes of people living with long-term illness or disability was recognized as a potentially important element of social connection for them. The continuity of personalized relationships between provider and recipient is known to be a fundamental condition for good care (Brechin 1998). With the restrictive regulation and speeding up of home care work, the basic health task of personal care is given ever higher priority and little attention or time is accorded to the relational context in which it is accomplished (Aronson and Neysmith 1996). These trends were very much in evidence in participants’ accounts and they felt their impacts acutely. As noted above, participants experienced cuts in their homemakers’ hours and, as a result, found them rushed and unable to provide the social contact that many had valued: “She hardly has time to say hello now.” Further, over the study period many women have experienced changes in their individual care providers — changes and discontinuities resulting both from CCACs’ shifting contractual arrangements with provider organizations and from the widespread instability in the home care labour force that has been generated by managed competition (Denton et al. 1999). As a result, the social connections and personal continuities that they valued were weakened or cut off: “I feel I’ve lost a friend.” They find “successions of strangers” entering their personal worlds and requiring constant (and tiring) explanations of the particulars of their needs and the organization of their homes. From home care users’ perspectives, such changes — rooted in apparently distant policy and organizational processes —
translate into loss of relationships, insecurity, and heightened isolation.

Some participants resisted these reductions of themselves and their social worlds by purchasing assistance and services. Many could not, of course, afford to do so. Half of the sample had low incomes and could engage in neither formal nor informal markets to supplement the help they received from public sources or from families. The pattern of poverty in this sample mirrors the wider distribution of income among elderly women and women with disabilities (Masuda 1998). Two women noted, further, that their isolated social circumstances made it difficult to locate help with cleaning; both were wary of advertising and dealing with strangers. The choices and purchases made by those who could afford to pay and could locate assistance are telling: deliveries of prepared foods either to offer others or to diversify limited diets; hairdressers who came to their homes to “make me feel more like a person”; cleaners to do a “proper clean”; companions for accompaniment outside and help to shop. Through such avenues, women attempted to buy inclusion and sociability. Those with sufficient resources could tap into one dimension of consumer-citizen conduct: the exercise of power through purchasing goods and services.

**Spatial Exclusion**

Participants spoke about their physical confinement in their homes: “Especially in winter, I feel like a prisoner here”; “It’s like being trapped”; “I can’t get out.” Such experiences of being physically excluded and out of sight resonate with others’ analyses of, for example, the “Hidden Geographies” of the worlds of women with multiple sclerosis (Dyck 1995) and of home care isolated “Behind Closed Doors” (Care Watch Phoneline 1999). Interestingly, in the European literature the spatial dimension of social exclusion has been concerned with the concentration of dispossessed populations in poor neighbourhoods in cities: in “no-go areas” (Littlewood and Herkommer 1999, p.16) unseen by the majority of the population. In contrast, long-term users of home care may be dispersed geographically — scattered in individual households — but they are similarly invisible in the no-go area of the home.

The home as an unseen site of social exclusion for frail elderly people and people with disabilities is fraught with contradiction and complexity. On the one hand, it is because of the privacy of “home” and its association with personal identity and security that people like those studied here hold it so dear: “I feel myself here; I belong. I’d dread having to leave.” On the other hand, it is its very privacy that imbues the home with the potential for problematic isolation and invisibility. Home care users straddle a complex boundary between public and private: their privacy is, in fact, already compromised as formal care providers intrude into their personal and bodily space. In care recipients’ and care providers’ daily lives and practices, negotiating this blurred boundary between private and public space is a matter of constant attention. Study participants describe such negotiation vividly, both when it is successful (e.g., when a familiar and knowing home care worker always used a bath towel to reduce an older participant’s exposure) and when it is not (e.g., when a new worker went through a clothes closet without permission or consultation with a participant).

The small literature on spatial issues at home care’s front line illuminates the complexities and demands of such negotiations for both service users and service providers (Baldock 1997; Gurney and Means 1993; Twigg 1997). However, their critical significance for recipients’ sense of dignity and control and for the skills required of providers seldom finds its way into discussions beyond the front-line level. Comparable attention to the implications of blurring public and private space — for evaluating services or for training workers — is not to be found among managers, planners, and policymakers. Indeed, the managerial discourse that dominates public administration prizes the simplification and standardization of service delivery, rather than its complexity and individualization (Clarke and Newman 1997). By not attending to complexity,
these groups effectively leave home care “behind closed doors” and do not take up as matters of public interest and responsibility questions of the quality of care and the accountability and preparation of providers. Thus, formal care provided in people’s homes, the care provided by families and the well-being of recipients are allowed to remain in the private, domestic sphere: out of the public gaze and outside definitions of public responsibility.

Institutional Exclusion
Study participants relate to a wide range of institutions and, given the narrowing of public commitment to all health and social services, found them increasingly unresponsive. They reported difficulties in accessing, for example, needed drugs, assistive devices and transportation services and, in some instances, struggled to find ways of absorbing their costs or of doing without. The CCACs are institutions of particular significance to participants’ living circumstances and encounters with them were a consistent focus of concern in interviews. Citing Kronauer, Littlewood and Herkommer (1999) identify the processes of “institutional exclusion” that can unfold in such encounters.

In their exchanges with their CCAC case managers, participants’ eligibility for service was assessed and reassessed over time. Most were told by their case managers that budgets were tight. Indeed, during the study period, many participants’ services were reduced, especially allotments of homemaking hours: “She took two hours off me. I had four and she took two. And my daughter phoned and said ‘my mother’s no different than she was when she had four hours!’ She said: ‘a government cutback.’” Case managers explained these reductions by referring to budget limits and by affirming that priority had to be accorded to medical rather than social needs: “She [case manager] said ‘there’s absolutely no housekeeping to be done’ ... she said ‘the government can’t cover that when so many people are really ill. You can have extra help if you want to pay. She can just help you with bathing ... that’s all.’”

Charged with rationing scarce resources, case managers use a medical discourse that questions the legitimacy of some needs and seeks to off-load responsibility for care from the public sector, to exclude wherever possible. At times, their efforts to exclude generated direct exchanges about the admissibility of participants’ needs and the legitimacy of their claims for help. For example, one woman tried to justify her need for more than the once-a-week bath. In a way she found demeaning, she felt forced to explain that she sweated a lot and that, in any case, she had bathed daily all her life and felt entitled to continue doing so, regardless of her arthritis.

Participants reported that case managers directed them to various alternatives to supplement insufficient CCAC support. Encouragement to turn to family members was commonplace and a reminder that the mixed economy of care often really means the care of relatives. As noted above and as is well documented in the literature, relying on relatives is seldom people’s preference and is done with reluctance and anxiety (Daatland 1994). Some participants’ case managers referred them to commercial care providers, assuming that they could pay. One participant, living in modest material circumstances, described her case manager’s effort to sound out whether she could pay privately for some of her care: “She asked me would I hire [my homemaker] and I said no ... because I’d just bought the hearing aid and, um, I mean, my savings are at an all time low ... At one point she said ‘couldn’t you even pay a little bit in?’” This participant minded the ambiguity of this exchange; in effect, it contained a discrete but officially quite unsanctioned means test that she resisted.

Responsible for accomplishing tasks within very tight time periods, care providers were also pressed to off-load work and responsibility, to close rather than open the gate to people’s requests for help. Thus, for example, a rushed nurse urged one participant to ask her building superintendent to administer needed eye drops. She was affronted at the assumption that, as a person with a disability, she could be asked to violate the bounds of normal
neighbourly behaviour and found herself “pleading” for the nurse to continue her visits. Several participants described tasks with which homemakers had once helped them that they were told were now off-limits. For example, the supervisor of another participant’s homemaker explained that taking out the garbage was no longer possible; she suggested that she ask her daughter to come over to put her garbage out for weekly pick up.

The inflexibility of a Meals-on-Wheels service proved a significant barrier for an elderly participant. The supply of her meals was switched from a hospital kitchen accustomed to her particular need for easily opened food containers to a private catering firm. Their containers defied the limits of her manual dexterity and, several times, she dropped them on the floor and missed meals. In response to her request for accommodation of her special needs, she was told that no one else had complained and that nothing could be done. Eventually, her physiotherapist, with whom she had a long-standing and trusting relationship, intervened on her behalf and she was switched back to the original provider. With no obligation to make their service accessible, the contracted commercial caterer could, without penalty and out of public view, rule this woman out. She felt her dismissal acutely and resented that things only changed when a professional advocated for her, that her own voice was not enough.

This last participant noted that this and other similar institutional encounters depressed her and, cumulatively, made her cautious about speaking up and expressing her needs. This muting process resonates with Littlewood and Herkommer’s (1999, p.14) conceptualization of “self exclusion”; it illuminates how structural forces become embedded in the framing of individuals’ identities and sense of possibility. Other study participants described, for example, how they censored themselves and, in certain situations, chose not to make their experience or their interests known. They observed with striking frequency in interviews: “You can’t complain, people don’t want to hear that.” When asked to elaborate and invited to “complain” in interviews, women spoke of distress, of the shame of feeling reduced and isolated and of the certain knowledge that no one could help them. “They ask how I am. I just say ‘fine.’ What would be the point?”; “I don’t tell anyone how depressed I feel.”

Some participants met institutional exclusions acceptingly, as all that could be expected. They took seriously their case managers’ explanations of service constraints and held out no hope of being included. For example, an elderly woman whose case manager had reduced her homemaking help and warned her of cuts to come fell and injured herself in her apartment. Despite her fragility and the practical struggles and risks that her fall exacerbated, she did not call her case manager: “She’d said I wasn’t eligible. I saw no point.” Some participants counted themselves out more actively, framing their behaviour in altruistic terms: “They’re so strapped for money, I said I’d try to help her (case manager) and make do with fewer hours; I know we’ve all got to tighten our belts.” In subordinating their own interests, they bolstered an identity they could still assert: as giving, attentive to others, self-sacrificing, and smacking not at all of the “dependence” that is so demonized in dominant political discourse.

These front-line encounters reveal the cumulative consequences of institutional and other exclusionary processes in lowering expectations and silencing people. Need as a basis for claiming public support is simply not admissible in the terms of policies and institutional practices designed to cut costs and off-load. Lack of funding operates as a rationale for turning to the market rather than as grounds for re-examining definitions of entitlement and access. Case managers’ efforts to divert elderly people and people with disabilities to their families or to the market constitute, for many, diversion into a vacuum. They are excluded; their needs go unmet.

**Cultural and Political Exclusion**

Institutional exclusions intersect with broader processes of cultural and political exclusion in
participants’ lives. The exclusion and disempowerment generated by cultural assumptions and social practices that privilege the able-bodied and the young have been made visible by the disability movement and activists concerned with the welfare of elderly people (Aronson 2000; Laws 1995; Morris 1993; Wardhaugh and Wilding 1993). Participants in this study felt excluded by their differences — their disabilities, their frailties, their old age — in a variety of ways. The younger participants with disabilities and two older participants who had lived with disability for most of their lives expressed themselves at times with indignant clarity, possibly because they had at their disposal a rights-based disability discourse: “There’s an unwillingness to see that disabled people can live normally — sometimes to see us at all, for that matter.” Older participants expressed their sense of exclusion with, usually, a tone of sadness and inevitability about losses of previously recognized identities and capacities: “I feel I’m nothing now, no one listens.” Several noted, too, the cumulative force of old age, frailty, and gender: “To them, I’m just an old woman — useless. I’m just waiting for the bone yard.”

This woman and other participants were acutely aware of their lack of power in relation to many of the institutions and individuals on whom they relied for assistance, the CCACs being, again, a central focus of their concern. Their encounters with case managers represented critical moments of need definition and negotiation of claims for help and were faced with apprehension: “I always feel edgy when they phone”; “I felt that her only objective was to cut wherever she could”; “I know I’m not supposed to but I think of her as the enemy.” Women’s responses to this precarious and anxious positioning varied. Some accepted it as inevitable: “I’ll just have to manage”; “How much can we really expect after all?” Others spoke in interviews of a sense of injustice and vulnerability that they did not actually express for fear of negative consequences: “You can’t bite the hand that feeds you, you know”; “You see, when you’re a recipient you’re not in the driver’s seat, not in control, you don’t have any options”; “You can’t get known as a complainer.”

Fear of getting known as a complainer and of its possible consequences meant that participants who had complaints were reluctant to voice them. Several noted that feedback was ostensibly invited in client satisfaction forms or in some case managers’ generally framed questions about “how are things going?” However, in neither context did they feel they could speak: “I don’t say anything; you can’t can you?” Many felt protective of their individual home care workers/nurses and, even if they found their work poor or their time insufficient, they did not want to appear critical of them as individuals; for example: “She [case manager] asked if I was satisfied and, really, I’m not. The girl’s quite slow and we don’t understand each other very well. But I give her ‘A’ for effort and I know she needs the work so I’m certainly not saying anything!”

The few participants who did complain or press their claims for help were not satisfied as a result. For example, an older woman complained about changing homemakers’ lack of preparation and orientation to her physical needs; she was told by her case manager that all provider organizations faced similar staffing problems and that there was nothing that could be done. Another felt “chastized like a child” by her case manager after she complained about tasks not included in her homemaker’s formal care plan (e.g., turning the mattress, doing hand laundry). Significantly, participants who felt in some way different expressed particular reluctance about speaking up on their own behalf. For example, the woman who struggled for accommodation of her special needs with meals on wheels noted: “Someone with as obvious a disability as mine — you don’t like to call attention to yourself — it’s better not to be noticed.” And a lesbian participant who felt her case manager disapproved of her observed: “I’m already on thin ice. I have to be careful.”

Advocates and activists press for making quality of care and equitable access to it matters of public concern. They seek, for instance, the introduction of transparent complaint mechanisms that assure confidentiality and that enable people to speak and,
further, that interpret complaints about individual workers in the full context of their strained working conditions (Barnes 1999; Meade 2000).

Significantly, women often asked in interviews how other study participants felt or negotiated their circumstances as care recipients at home. They had few opportunities to develop a collective identity in the face of their disempowered and isolated positioning. In her study of women with multiple sclerosis, Dyck characterizes women’s everyday worlds as “spaces of silence”: “hidden from view and commonly separated from others in similar circumstances” (1995, p. 308). Among the participants in this study, the silence among the older women was especially marked. While their younger counterparts used a language about disability rights, many of the older women had little sense of collectivity and saw themselves as deficient and burdensome. One woman who had previously belonged to a seniors’ advocacy group commented: “It feels so different now. I’ve no energy; my body’s let me down. I’m on my own with this.” On her own, this woman’s identity had become confined: no longer participating in the wider political or social surround as a citizen but atomized and isolated as a service user. Such subordination and reduction of identity is embedded in the health discourse that dominates home care users’ lives, counting them as nothing but their everyday functioning and failure to be self-sufficient.

It would be wrong, however, to interpret the cumulative exclusions experienced by this sample as only silencing and defeating. Even as this last woman’s physical orbit, social ties, and expectations of help dwindle, she remains determined to stay at home and marshals whatever resources she can to do so. Some participants write letters to their MPPs, newspapers, and municipal governments about their concerns. Many resist exclusion through creative, everyday negotiations to expand their orbits and get their needs satisfied. Such day-to-day negotiations are often accomplished with the help of attentive care providers who are willing to break or bend official rules by, for example, giving a home perm, preparing food “for company” or doing hand laundry. Several participants reported, too, how rushed care providers gave them extra (unpaid) time to expand the limits of their rationed care. Such hidden and evasive forms of resistance are the resort of the powerless. Their costs are borne by those excluded from channels of official influence in the formulation of practices and policies in community care.

DISCUSSION

This study of the experiences and knowledge of home care of women who are elderly or live with disabilities illuminates how they are pushed to “live on the edge” — at the social margin — and reveals managed community care as a critical site of their exclusion. The theoretical and research literature on social exclusion has concentrated heavily on the exclusions of poverty and its conceptualization of inclusion has, in turn, been heavily employment-related (Levitas 1996). This analysis of the excluded positioning of elderly women and women with disabilities living in their own homes adds to the literature seeking to explore how exclusion happens to differently marginalized populations and requires conceptions of inclusion and citizenship that rest on broader forms of social and political participation.

We have focused on women “excluded” in order to understand how their exclusion is accomplished. As Byrne observes: “Exclusion is something that is done by some people to other people” (1999, p.1). It is an active process not simply a “label to be attached to the casualties of some impersonal processes of urban-industrial change” (Room 1999, p. 172). Our purpose is to further understanding of how we, as professionals and public policymakers and analysts, manufacture exclusion. The spotlight is on us not them — on our practices and analyses, not their characteristics or adjustments to them. As a first step in considering an inclusive policy for community care, it is critical that we recognize both the hollowness of community-care policy as
presently implemented, managed, and delivered, and the deceit of redirecting elderly people and people with disabilities toward families and markets as if their admission to these private portions of the mixed economy of care is unproblematic and their access to needed care in these arenas assured. It is also critical that we recognize the implications of confining public policy in community care to the health care arena. This narrow sectoral perspective cannot possibly address the broad-based social and political exclusions experienced by the women studied here.

In the present mixed economy of care, women such as this study’s participants are, as we have seen, construed as “consumers” or “customers.” This construction rests on false assumptions about their capacities to navigate the home care marketplace on their own. The persistent focus in home care policy on self-sufficiency, family, and the market directs attention away from debates about citizenship that would challenge the legitimacy of the consumer/taxpayer as a basis for making social claims. If public services are not distributed on the basis of need to people entitled to support but, rather, to consumers then citizenship is denied. We are not presenting the experiences of this study’s participants as documentation of what is happening to the casualties of failing social policies. It is not these women or the policies that are failing. Indeed, the policies are succeeding in their own terms in reducing public responsibility for care and reframing citizens as consumers (and participants attest to the costs that such exclusionary policies and practices lay at their doors). The failure is, rather, one of political commitment to developing needs-based social-care policies where responsibility rests not with family, volunteers or the market but firmly in the public domain of social policy-making (Lister 1997).

As we move away from a market discourse that contributes to and manufactures the social exclusion experienced by the participants in this study, two key challenges emerge for future debate and research. First, determining whether policies and programs actually achieve inclusion will be difficult. Room proposes examining whether they really offer “stepping stones back into mainstream society” (1999, p. 172) or whether they simply confirm people in a marginal existence. In the context of community care, disability rights groups are highly attuned to this distinction; it is crystallized in the words of a woman in Morris’s study of community care in the United Kingdom: “They seem to think that community care is about someone being cozy and comfortable, being kept clean. To me that’s a step back into the situation of residential care — living in the contained environment of your own home. If you don’t broaden it out it isn’t independent living” (Morris 1993, p.161 ). The mixed economy of care available in the community today does not “broaden it out”; indeed, the space to claim help on the basis of need (rather than ability to pay or availability of unpaid family members) is narrowing and people with disabilities and elderly people find themselves “on the edge,” struggling with unmet needs in isolation. Including in policy development the analyses of those who know and use community care can enhance its inclusionary potential and likelihood of being really “broadened out.” Beresford and Wilson (1998) note the irony that groups seen as excluded are seldom heard in discussions of social exclusion. They argue that including them will ensure more informed debate and “a more rational and democratic basis for priority setting” and lessen the risk that they will be objectified and viewed as “less than fully persons” (Beresford and Wilson 1998, p. 91).

The second challenge in working toward inclusive community care concerns relatively advantaged groups — those presently “included” — and whether they will support more inclusionary policies. The entrenched oppositions in dominant political discourse between independence and dependence, taxpayer and service user, and us and them, and the associated withering of shared institutions of citizenship mean that relatively privileged groups have less connection or identification with the excluded. These conditions make possible what Tronto (1993, pp. 120-21) terms “privileged irresponsibility”:
“Those who are relatively privileged are granted by that privilege the opportunity simply to ignore certain forms of hardship that they do not face.” At the same time, though, the number of Canadians who will experience or witness the exclusions of market-modelled community care — as care recipients, family members, friends, home care workers — is increasing and will continue to do so in the future. Their concerns are most commonly taken up by advocacy groups and social movements of various kinds. Policymakers, policy analysts, academics, and activists all have a part to play in challenging ill-founded oppositions between taxpayers and current service users and bringing the realities of interdependence and care, rather than limited images of self-sufficiency and self-interest, into public policy discussions.

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