“I Don't Want To Be a Burden”:

Needing Assistance in a Context of Disentitlement

By Jane Aronson

I don’t want to be a burden” is a statement commonly made by old people. It rings with familiarity as I think of women I have watched growing old in my family: my grandmother, aunts, godmother, my mother. I have heard it spoken, too, among older women taking part in an ongoing research project on their experiences of emerging needs and challenges as they age. If we delve behind this terse statement, we can identify some realities about the current social context facing old women. Being ‘burdensome’ would, logically, mean imposing or depending on others whose assistance or willingness to help cannot be assumed or counted on. The words suggest a lack of confidence, a lack of entitlement to a supportive response. They are also other-centered rather than self-centered; the focus is on curbing demands or claims on others, rather than on the needs of the speaker.

That elderly people may need help or support of various degrees is well-known. While aging is certainly not an inevitable downward progress and the necessary association of old age with ill health has been properly dispelled, it is probable that for many health and ability will lessen with increased age. Health concerns and lessening capacities can translate into needs for a range of assistance and support—from help with everyday household tasks to negotiating the physical environment outside the home, to aspects of personal care—that will depend on people’s particular activities, environments and resources. These emerging and changing needs are especially characteristic of the very elderly, among whom women predominate now and will do so for the foreseeable future.

How is it then that, on the one hand, a slowing down and lessening of capacities is expectable and normal while, on the other, many older women share an expectation that receiving needed support may be an imposition rather than a taken-for-granted entitlement?

This article explores this uncomfortable and unfair tension. In interviews with older women in a variety of circumstances (health, age, living situations, family contexts, income, experiences with health and social services, engagement in social and political activities), I have gathered their accounts of the prospect of old age and possible frailty. Depending on their circumstances, women talked about the prospect or experience of turning to health and social services for needed help or, much more commonly, to family members, usually daughters or daughters-in-law. The views and concerns that they voiced about these processes often revolved around the notion of being burdensome or disentitled. Many took for granted this troubling sense of weighing on others, feeling that it was up to them to cope well, that it was a particular feature of their family situation or that it was simply an inevitable part of growing older to be endured. Others resisted this sense of inevitability, looking beyond their own immediate personal worlds and reflecting on ways in which the experience of old age could be one of security and confidence, instead of precariousness and disentitlement. Their comments and the insights of older women writing about their own aging challenge us to look beyond the status quo and envision other possibilities that can enhance women’s autonomy in later life.

The Prospect of Needing Assistance

Faced with the prospect of needing assistance of some kind, families emerged in women’s accounts as the first line of resort and the most enduring source of assistance: “I don’t know what I’d do without my daughter—she’ll keep me going here;” “I’m very lucky to have my niece. She comes in regularly and does all the things I can’t do;” “I feel so sorry for [friend]. She has no children to turn to now.” The reality that most of the care of old people is provided by families and, within families, by women is reflected clearly in these observations. Publicly-provided services (supportive services at home, various forms of institutional care) remain very much in the background and, with cuts in spending on health and social service programmes, are likely to remain so.

A number of the women I spoke with had been recipients of home care services (homemakers, meals on wheels, visiting nurses). They all welcomed them, but recognized that they were in short supply: “When I came out of hospital, I had a homemaker for a bit. She was good... it got me over the worst.” Another woman explained that, after such short-term help at home, she and her daughter negotiated with the homemaker to continue coming after medicare coverage of her services ended. The ability to afford such private solutions to emerging needs is generally not an option for elderly women, a large proportion of whom continue to live near the poverty line. For this woman, the privately-paid homemaker meant that she could just manage to live in her own apartment and not face the prospect of “a home.”

Apprehension and “dread” at the prospect of institutional forms of care was voiced by many of the women I interviewed. Associated with being “herded together,” it was seen as surrendering control and a last resort: “What else was I
"If an old woman talks about arthritis or cataracts, don't think old women are constantly complaining. We are just trying to get a word in edgewise while you talk and write about abortions, contraception, pre-menstrual syndromes, toxic shock, or turkey basters."

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between women of different generations for solutions to older women's needs. Pressed into such ties by the absence of alternatives, it is no surprise that women often experience them as tense and unwelcome; we have seen how, for older women they generate feelings of burdensomeness and shame and, for younger women, feelings of obligation and guilt. Just because the present pattern of care presses women into these ties of dependence and responsibility does not mean that alternatives are not possible: men could share equally in caring for others; public services could be provided in ways that afford old people choices and the right to exercise them.

On the latter point, we hear a great deal from federal and provincial governments about long term care reform and policies and plans for health and social services for an aging population. Central to such reforms is the effort to keep old people out of institutions and in their own homes. Community services and home care programmes are heralded as the solution to old people's needs — albeit with meagre commitments of resources. Community-based and institutional types of care for old people are depicted as opposites: community care is portrayed as good, cheap, humane and preferred by old people, while institutional care is seen as bad, expensive, inhumane and disliked by old people.

In light of the comments of some of the women I spoke with, the range of possibilities that these policy developments provide for (and the assumptions underlying them) seem very narrow and simplistic. While many women certainly spoke of their "dread" of institutions, others pointed out that what they feared was the loss of control and impersonality that is characteristic of institution and would feel more secure:

"I think a home in which there are half a dozen people and one person or two to look after them...that person is their employee, not the manageress, because then that little bit of bossiness comes in."

In these comments, we see the possibility that institutional care could be reframed — that it could enhance rather than jeopardize autonomy. The disempowerment associated with institutions and their negative images has, however, promoted ready acceptance of non-institutional alternatives whenever possible. Earlier, we saw how one elderly woman reluctantly reconciled herself to accepting her daughter's help, if that would fend off the spectre of "a home." Fending off that unwelcome prospect perhaps has led us to be very undiscriminating about community-based care, too, accepting it as preferable without real scrutiny. Several of the women I spoke with challenged this unquestioning acceptance. For example, one woman speculated that staying at home with a few services coming in would be very isolating:

"I know that's the trend (community care) but I wouldn't like it. I imagine it'd be lonely. For example, there's a woman down the hall whom I take for a walk sometimes. A homemaker and someone from VON go into her. The other twenty-three hours she's quite alone."

Another questioned whether receiving services at home would necessarily foster a sense of control or independence, as is commonly claimed:

"When you're an old lady, frail, maybe a little bit helpless, you haven't got the gumption to stand up against a person who's coming in to do a service and say: "That wasn't good enough." You just let it happen."

These women's questions are driven by needs for security, control, autonomy, choice and a balance between privacy and companionship. Their articulation of these needs blurs and complicates the formulaic notions of 'community' and 'institution' that dominate current debate and planning for the care of old people.

In her "critical reflections on growing old," Doris Marshall notes that services and responses to the elderly are: "...the result too often of planning for old people, without input from them."

"Ensuring input and participation in the future will be no simple task: we have seen how commonly older women feel silenced and jeopardized, and how little, when able to speak, older women's concerns correspond with the directions and assumptions of health and social programmes. Calling women of all ages to begin the task and to work on our ageism, MacDonald urges:

"Don't think that an old woman has always been old. She is in the process of discovering what 70, 80 and 90 mean. As more and more old women talk and write about the reality of this process, in a world that negates us, we will all discover how revolutionary that is."


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