The Shifting Balance of Long-Term Care in Sweden

Gerdt Sundström, PhD, Lennarth Johansson, PhD, and Linda B. Hassing, PhD

**Purpose:** This study describes the Swedish debate on the role of family and state in care of elderly persons. It provides empirical evidence on the shifting balance of family, state, and market in the total panorama of elderly care. **Design and Methods:** Secondary analysis of older (1954) and more recent data sources (1994 and 2000) is used to assess living arrangements and care patterns for persons 75 years or older living in the community. **Results:** Total spending on aged adults has stagnated, and institutional care is shrinking in absolute and relative terms, but public Home Help for elders in the community is decreasing even more. Family members increasingly shoulder the bulk of care, but privately purchased care also seems to expand. **Implications:** The results parallel a crisis of legitimacy of public elderly care in Sweden. They also call into question various metaphors used to describe patterns of care.

**Key Words:** Informal care, Family, Home Help, Welfare state

One of the oldest discussions in gerontology and, indeed, in social science concerns the role played by the state and the informal network around elderly people in need of help and support and how this has changed. Welfare states like Sweden have been thought to represent paradigmatic cases of special interest.

Swedish policy makers are now worried about rising burdens of care and pension expenses, and a recent major reform of the pension system has reduced its “pay-as-you-go” structure. The new system has a savings (funds) part to it, and the individual return from the system will be based on lifetime earnings and on general economic growth.

A peculiar trait of Swedish society used to be the unquestioned mutual trust between individuals and the state, demonstrated for example in opinion surveys that showed substantial willingness to pay taxes for public elderly care. Recent cutbacks in services for elderly people have undermined this tacit “contract,” and there are many indications that these changes lead to a new balance of responsibility for elderly people. Opinion polls indicate declining trust in public pensions and public elderly care.

There is a dearth of theoretical analysis of the relationship between informal and formal care in a welfare state of the Swedish kind, but thinking about these things seems to be much the same as in other countries. How we conceive of the situation of elderly persons is often a subcategory of ideas about the family and the state in general (Berger & Berger, 1983). A common assumption seems to be that they relate as players in a zero-sum game—where one wins, the other loses. There are various metaphors of how one form of care substitutes for another, but the mechanisms often remain elusive and empirical evidence is lacking or contradictory. Thus, it is often said that the state has taken over what the family used to do, although some analysts maintain that the family could not or would not always provide care, or did it poorly. Others believe that the state crowds out the family, much in the way inferior coins used to drive out of circulation coins with more silver/gold in them.

Yet, metaphors can be misleading. For example, the little evidence we have so far indicates that both kinds of care expanded in postwar years, if for no other reason than the nearly trebling number of elderly people. Furthermore, both kinds of care seem to have raised their quality. Common metaphors have trouble handling scenarios like that (Lingsom, 1997). Another school of thought sees these two kinds of care as complementary rather than supplementary. In a related vein, one early analysis of these issues concluded that families and the state shared tasks of care and, in a sense, could—and should—support each other (Moroney, 1976). It has even been suggested that increased public services for elderly adults implied...
more, not less, informal care, and these very services might improve, rather than impair, intergenerational relationships (Johansson, 1991; Künemund & Rein, 1999; Sundström, 1983).

To complicate the issue further, some theorists would rather argue that families, the main provider of care, by and large live their own lives unaffected by or indifferent to what takes place in the public sector. This would make concepts like supplementarity and complementarity more or less meaningless, with their assumptions of “hydraulic” interdependence. If so, larger or better public services may be respite care for families and elders, but not much more.

Sweden is a good test case for thinking about these issues, because the state has invested heavily in public support to, among others, elderly people. In 1987, it was officially stated that informal care was a supplement to public services when the government proposed a new support program for care providers (Government proposal 1987/88:176, p. 92).

One clue to the balance between state and family is public expenses for elderly people, convenient in the Swedish case where nearly all spending on elderly adults is channeled through public bureaucracies. The legal obligation to provide for parents (and parents’ obligations for adult offspring) was lifted from the Poor Relief Act in 1956 and the Family Law in 1979, long obsolete even then.

In 1950, pensions had just been raised to a level that made them possible to live on, and housing allowances were introduced. By that time, about 5% of Sweden’s gross domestic product (GDP) was spent on elderly persons (a total of pensions, housing allowances, social services, and health care). This expanded to roughly 14% of the GDP in the 1990s, but has since stagnated and is unlikely to expand further in the near future, judging from budget forecasts and constraints on public spending (special calculations by these authors).

Impressive as this growth in spending was, it remains that the number of elders grew at about the same rate, and other countries are not lagging far behind in spending. The undeniable rise in standards of living that elderly adults have enjoyed in Sweden is rather the result of generally rising standards. Spending patterns do not explain why coverage rates of services culminated in the 1970s, with a gradual decline thereafter.

An overview of public care for the Swedish elderly population shows that, in 1950, one fifth of the oldest segment of elderly adults (20% of those persons 80 years or older) was institutionalized. These elders were typically persons with weak family ties: They were mostly childless and poor, and 51% of them were never married. Indeed, this was still classic poor relief, but change was under way. The first public scandals of elderly care raised awareness of these issues and Home Help expanded very quickly in the 1960s and 1970s, as did institutional care. In 1975, 30% of persons 80 years or older were institutionalized, and 38% used Home Help (Swedish Institute, 1999). Thereafter, coverage rates declined, especially during the 1990s and for the Home Help service: In 2000, 21% of persons 80 years or older were institutionalized, and 19% used Home Help. It should be noted that elderly care in Sweden is a local undertaking and responsibility, with considerable local variations.

Old surveys of the elderly population—as far as is known, Sweden has the oldest (1954) representative survey of any country still open to analysis—shed light on social aspects of aging during this long time period. Selected information in Table 1 describes trends in living arrangements.

Of course, the same trend is observed in other countries, although usually at a later stage in time. Over the years, more elders live alone (but usually with offspring living nearby), more live with their spouse only (51% of persons 65 years and older in 2000), and fewer live with their children or other persons.

Clearly, ideological and political statements do not always steer the actual handling of social issues, whether by individuals or governments. For example, in Sweden, during the 1800s, when offspring were legally compelled to care for parents, sometimes they were paid by the local poor relief boards to do so. The shifting household patterns described previously did not diminish the informal care that Swedish elders still enjoy. Cross-sectional studies report positive, not negative, correlations between public services and help from family members (National Board of Health and Welfare, 1994, 2000a, 2000b). In the few Swedish studies where individuals are followed longitudinally, it emerges that the more help the elderly population needs, the more help they eventually get, from all kinds of sources (National Board of Health and Welfare, 1999).

Home Help was, and still is, the most important service to needy elders living in the community. This needs-assessed, but not means-tested, service provides both home-making services and personal care, that is, help with household tasks and assistance with personal care. Fees are charged according to income and hours of help used. Calculations on national statistics indicate that the average input of Home Help is about 32 hr/month, with a very skewed distribution (see later). This is confirmed by information of the subjects surveyed, although they report a somewhat lower average level. (Most clients use less than 10 hr/
month.) Multiple regression analysis has found elderly users to be very old, frail, and living alone, with relatively small social class differences (National Board of Health and Welfare, 2000a).

A local Swedish study of elders 75 years and older residing in the community in the 1980s calculated informal care by assigning it to the same number of hours as when the same task was done by the public Home Help services, task by task. This procedure obviously disregards all care typically not performed by public agencies, but conducted by families, such as monitoring, home maintenance, etc. Still, it was found that 68% of all care was provided informally (Johansson, 1991), a proportion that is in line with several other studies (Kane, 1990). A similar approach is used in the present study.

Over a not-too-extended period of time, it should be possible to produce estimates of quantitative change in that proportion, and in the direction of that change, if any. In an attempt to achieve this, we will scrutinize the situation in Sweden during a period of rapid shifts in public services in the 1990s. This may help us understand how people use public services and get informal care. It may also enable us to assess the relative weight of formal and informal support and how they relate to each other. We know that it takes time for the elderly population and their families to accept and accommodate new social services. The results of cutbacks in services are much less known. Have cutbacks meant a transfer of care (back) to families or is the observed shift merely a marginal change of the (assumed) equilibrium and partnership between formal and informal responsibilities?

In 1992, a major reform of Swedish elder care placed all elder care strictly with the municipalities, be it institutional care or whatever kind (apart from pure acute care in hospitals) or services for elders in the community. It also made municipalities financially responsible for elders who hospitals want to discharge. In one stroke, this reform nearly did away with the problem of bed-blockers (Johansson, 1997). Yet, during the financial turbulence of the 1990s, many municipalities had to face declining fiscal revenues and therefore raised copayments for users and introduced stricter needs assessments. This is likely to be a major explanation of declining community services. In this study, we will disregard changes in institutional care, because its coverage rate changed little between 1994 (23%) and 2000 (21%) for the old-old adults (80 years and older) and also because informal care for a number of reasons may not be an alternative for many of the residents in these settings.

It is intriguing that cutbacks have been greater for the much less costly Home Help service than for institutional care. Home Help is designed to help elderly people remain in their own homes and to be a cost-effective program. Cutbacks in this service contradict official policies at both the national and local levels of supporting elderly people at home, policies that emerged after the previously described public scandals of institutional care in the 1950s.

Methods

We will draw both on official statistics from social services and from surveys of elderly people. As indicated, Swedish municipalities are responsible for all public elderly care and provide nearly all Home Help services, institutional care, transportation services, security alarms, meals-on-wheels, and other services for elderly people and the handicapped. For Home Help and institutional care, there is reasonably good annual data at both the local level (the 289 municipalities differ a good deal in coverage rates) and for the national average.

The surveys used are from the 1994 and 2000 national surveys of elders 75 years and older living in their own homes. These are representative, in-person interviews (N = 1,379 and N = 1,466, respectively). Subjects are weighted, as men and the oldest segments were oversampled (no upper age limit). The surveys, that covered a wide range of issues, were conducted for the National Board of Health and Welfare and in all important respects were similar in design and item use. The first survey had a drop-out rate of 27%, the second 30%.

Details on the surveys are given in the official reports (National Board of Health and Welfare, 1994, 2000a), but there were no indications of drop-outs causing substantially different biases in the two surveys. The very frail and sick may be underrepresented, but the surveys do include a sizable proportion of persons with cognitive dysfunctions, and the fraction of frail elders is on a par with results in other national surveys of Swedish elders.

As previously described, we will utilize information on public Home Help used by subjects in these surveys as a benchmark for comparisons. The surveys register whether subjects use Home Help, with which tasks, and the total number of hours received/week. Our estimates of the Home Help input are restricted to support with the range of activity of daily living (ADL) functions covered by the surveys (see later data). All of these ADL functions are indexed for the subjects and the number of Home Help hours for each level assessed, with a distinction between those persons who use Home Help only and those who also receive informal care. There is no information on the number of hours of informal care, only on who provides help with the specific tasks that are being performed informally. The elderly adults are assumed to receive the same amount (number of hours) of help informally as from the Home Help service. (A growing, but still small, proportion uses out-of-pocket paid private help. They are disregarded in the following data.)

Obviously, these ADL categories of help are not exhaustive, and the assumption of equal inputs from the social services and informal providers can be disputed. We also neglect time and effort spent on other types of support. Our estimate of informal care will therefore be conservative and probably more so in the more recent survey: It was found that, in 2000, less Home Help was provided for a given ADL level of
need than was provided in 1994 (National Board of Health and Welfare, 2000a). Another potential bias derives from more Home Help being provided to persons living alone—everything else being equal.

Results

In the 1994 and 2000 surveys, need for help was assessed with 10 ADL items (see note to Table 3). For each need, it was established who was providing help. The helper’s gender and relationship to the interviewee were registered, and it was established whether Home Help was provided with these tasks. The total number of hours of public Home Help was also determined. Before assessing amounts of care, we assess the totality of care, as shown in Table 2.

Clearly, a growing fraction of elderly people relies on informal care only, and a shrinking fraction depends on public help, be it alone or in combination with informal care. Among coresident elders, little shift has taken place in care patterns: now as before, most find their care provider in their own household. This is usually the spouse, and there are in absolute numbers about as many men caring for wives as women caring for husbands (National Board of Health and Welfare, 2000a).

The proportion and number of elders that live alone have expanded, and it is in this group that the large shift from formal to informal care has occurred. The Home Help services have always targeted elders who live alone, but they no longer dominate the panorama of care. Mostly, this is a consequence of the general decline in these services.

The surveys undertaken in 1994 and 2000 can also help us assess the volume of hours provided to elders by various sources of care. To this end, needs for help with various ADL tasks were converted for all interviewees into a straightforward index (Table 3), in which a higher value indicates that the person managed more ADL functions on his/her own. The total number of hours of Home Help per week provided to each subject is known. Index values were collapsed into three categories—low (0–3), middle (4–6), and high (7–9) functional capacity—with the Home Help input averaging around 14, 7, and 2 hours/week, respectively.

As mentioned previously, we assume that elders who needed help but used no Home Help received at least as many hours of help from informal care providers at their respective ADL level, because they would have received Home Help at that level had they used this public service. This will not inflate informal care and will give a conservative estimate of decline in public services, if anything (very few persons reported needs that were not taken care of). Subjects who used both Home Help and informal care are assumed to have used the same number of hours of both kinds. Calculations are based on the actual hours of Home Help reported. Closer inspection reveals that the frailest subjects in the combined category are more cognitively impaired (lower Mini-Mental State Exam scores) and the combined category is on the whole more frail in ADL terms. (The figures for this category in Table 3 refer to Home Help plus informal care.) The aggregate outcome of this operation is presented in Table 3.

Under these assumptions, it emerges that public Home Help provided 40% of the total amount of help hours in 1994 and 30% in 2000. We can also use these survey data to estimate the annual amount of help for all elders 75 years and older in the population. Thus, if we convert the weekly figures to annual ones, the Swedish municipalities in 1994 produced 36 million Home Help hours for those elderly individuals 75 years and older. In the same way, 28 million Home Help hours were provided in 2000. Likewise, under these assumptions, informal care providers raised their output from 50 million hours in 1994 to 61 million hours in 2000.

Table 2. Sources of Care for Swedish Elders (75 Years or Older) in Need of Help and Residing in the Community, by Household Structure: 1994 and 2000 (%)

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<tr>
<td>Family/informal care only</td>
<td>59 72 56</td>
<td>66 82 67</td>
<td>33 47 36</td>
<td>47 64 45</td>
<td>85 88 87</td>
<td>88 88 87</td>
</tr>
<tr>
<td>Both informal care and Home Help</td>
<td>13 16 14</td>
<td>16 16 16</td>
<td>17 24 18</td>
<td>24 24 24</td>
<td>9 11 10</td>
<td>7 9 7</td>
</tr>
<tr>
<td>Home Help services only</td>
<td>28 41 29</td>
<td>18 34 19</td>
<td>51 28 51</td>
<td>28 28 28</td>
<td>5 5 5</td>
<td>5 5 5</td>
</tr>
<tr>
<td>Total</td>
<td>100 100 100</td>
<td>100 100 100</td>
<td>100 100 100</td>
<td>100 100 100</td>
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<td></td>
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<tr>
<td>n</td>
<td>538 642 266</td>
<td>338 303</td>
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Source: Computations on surveys from the National Board of Health and Welfare (1994, 2000a).
Nevertheless, the estimates appear to be reasonably consistent and reliable. Nevertheless, the estimates appear to be reasonably consistent and reliable. Nevertheless, the estimates appear to be reasonably consistent and reliable. Nevertheless, the estimates appear to be reasonably consistent and reliable.

It is obvious that calculations of these kinds, whether they use survey data or derive from official records, can only be seen as crude estimates of patterns of care. Data of these types say as much about help provided as about what is not provided. Yet, all observations point in the same direction. Public spending on care and services for the elderly population and especially for those living in the community has not increased over the last decade. Coverage rates for Home Help services—the most important, but not the only, community service—have decreased. More importantly, estimates on hours of help also indicate that a shrinking fraction of the total amount of care is publicly provided, at present (2000) about 3 hr out of 10.

As indicated (Table 3), these estimates refer to informal care and help only with the ADL items that were included in the surveys and assign no time at all to any other type of help and support provided by families and other informal carers. Public Home Help, on the other hand, is covered completely. For example, monitoring is extremely time-consuming when done by public agencies—and therefore rarely done (but included here if done)—but goes unnoticed when done informally. On the other hand, few of the elders who rely only on Home Help report unmet needs. This supports our assumption of at least basic substitutability between formal and informal care case-by-case, even if an hour-for-hour relationship is unrealistic (Tennstedt, Harrow, & Crawford, 1996).

Both in 1994 and in 2000, the surveys established that a sizable and growing fraction of the Home Help users were cognitively impaired. This latter year, these clients used nearly half of all Home Help hours that were provided. Judging from a study on elderly dementia victims and their informal care providers, the latter spend about 2 times more hours on activities other than those covered by ADL estimates (National Board of Health and Welfare, 2000b). This may be extreme, but underscores the conservative tendency of our estimate of informal care; in all likelihood, it has expanded even more than indicated here.

Interpretation of these shifting patterns of care is even more problematic than emerges from coverage rates (Table 2) and from amounts of care (Table 3). Even if local municipalities provide less Home Help, there are other ways to uphold contact with elderly citizens than we can deduce from these coverage ratios. In the last 10–20 years, other types of services have expanded greatly and are often used by persons who do not use Home Help. Transportation service is used by 29% of the 75+, security alarm systems by 126, meals-on-wheels by 50, and so on.

Often, but not always, these services are provided after needs assessments in the client’s own home, and they overlap only partially between themselves and with Home Help. The total coverage rate of elders who benefit from some kind of public support is therefore roughly the same today as it was around 1975 (see previous data; National Board of Health and Welfare).

Table 3. Average, Aggregate Help Input (Hours/Week), for Elders (75 Years or Older) With Different Combinations of Support, Living in the Community: 1994 and 2000

<table>
<thead>
<tr>
<th>Type of Support</th>
<th>1994 Home Help and Informal Care</th>
<th>2000 Home Help and Informal Care</th>
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<tbody>
<tr>
<td>Only Home Help</td>
<td>1,302</td>
<td>465</td>
</tr>
<tr>
<td>Informal Care</td>
<td>1,929</td>
<td>929</td>
</tr>
<tr>
<td>Total</td>
<td>3,231</td>
<td>2,177</td>
</tr>
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Note: Hours of help are assessed for three subgroups of dependence in ADL functions and then added up. Figures on hours of Home Help are consistent with other Swedish studies on Home Help that have used the same ADL index. Functions used for the ADL index are: need for help with shopping, cooking, cleaning, laundry, getting into/out of bed, bath/shower, dress/undress, toileting, eating, outdoor walks—needs personal assistance. The index is a simple cumulation of number of functions subject manages on his/her own without help. ADL = activity of daily living.

Source: Computations on surveys from the National Board of Health and Welfare (1994, 2000a). n (weighted): *126, +50, ‡322, §102, †81, and ‡425.
and Welfare, 2000a). It may be argued that these other services do not always provide adequate substitutes for real Home Help, and it remains that the welfare state is now generally rationing Home Help services and gives priority to the most frail and needy. Clients get less Home Help than before, even for the same needs (National Board of Health and Welfare, 2000a).

An interesting aspect of these shifting patterns of public and informal care is an apparent increase in sharing of the tasks between Home Help and informal care providers (Table 2). This is largely because fewer elders can rely only on Home Help, and more of them (have to) rely only on informal care. In more solemn moments, one used to say that solidarity in the welfare state meant that family and state go together. The idea in the 1980s that the state could and would provide nearly all care, with the family as just a supplement (see previous data), now appears as an overheated rhetorical figure typical of that epoch.

The fact that families provide a growing part of care for elderly adults and that the state has withdrawn its flagship, the Home Help, from central areas of support to Swedish elders has already led to questioning of the legitimacy of this service and pressure group formation. Also, other nonpublic alternatives emerge and, as mentioned, privately purchased help expands among elder adults. The tacit contract between family and state is less tacit today and is increasingly called into question.

Taken together, this changing pattern of care implies doubts as to the validity of all the various metaphors of the balance of formal and informal care. It seems likely that the elderly people themselves should be seen as active agents: What are their preferences? Why do they sometimes accept help from family or purchase private help rather than use public services? The latter charge fees that are often perceived as high, and some (would-be) clients feel they do not provide appropriate value for the money. The consumers have to be brought back in, if we are to understand their choice of support (Tennstedt et al., 1996).

In conclusion, the welfare state has retracted its more far-reaching ambitions. The question is whether it has also resigned from a basic but mostly silent premise of the welfare state: the idea that public services support and strengthen informal structures and that they are mutually reinforcing. This has been called solidarity (Sundström, 1983), but it is also a matter of everyday social policy, as practiced in myriad local cases of help to aging persons. Both individuals and families have received support, and caring family members usually could trust that they would not stand alone with their tasks and commitment. Ever more strict rationing of these very services and the increasing focus on individuals that live alone and may have no family to help them jeopardize the silent understanding that the state and family are partners in this undertaking. This may, in the not-so-long run, undermine the welfare state itself.

References

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