Reflections on Long-term care in Sweden

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Foreign visitors to Sweden are sometimes impressed (and irritated) by the orderliness of social life. It is hard to exactly define the meaning of this, but it may have its root in the history of the country, and the culture this created. Swedish culture was and remains quite homogeneous, helped by the reformation and early efforts to teach parishioners to read: to receive the word of God directly from the Bible is important for protestants. (Compulsory public schools started in 1842). After the reformation state and church were united. Parishes – a both religious and geographic-administrative unit in the Nordic countries – were by law to provide for their sick and poor, who had no family to do it for them. Parishes collected taxes for this purpose, had meetings with locally elected parish members to decide on the use of the funds, and kept records. Systematic, public, locally financed and

relatively autonomous but compulsory local care for the poor is thus a very old feature of Swedish society. The modern welfare state has old roots and in many ways follows the path of the past. When this took form in the late 1500s Sweden had just 750,000 inhabitants, in 2,500 parishes; hence everybody would know (about) everybody else in the parish. When reliable population records – kept by the parish – started in 1749 Sweden had only 1.8 million people. Poor relief was often quite extensive, and it is easy to find areas in the 1800s which had the same institutionalization rate (4-5%) of older people as today.

The state used the well-organized church-state administration to draft soldiers, control morale and abidance of the law, collect national taxes etc. until 1862. Then the new secular municipalities "took over", but still functioned much the same way and remained geographically the same units, thus preserving an important identity. In year 2000 church and state were finally separated. The Nordic countries have a simple administration with a strong central state, and strong local units (which do not always follow central directives), with weak intervening layers between them. Most personal tax (ca. 31% of income) paid in Sweden is municipal tax, only the minority with high incomes (about 50,000 euros/year) also pay 20% state tax.

As indicated, there have been cutbacks in institutional care. Needy persons are expected to manage longer with Home Help and/or other "minor" services such as transportation services, alarm systems, meals-on-wheels, day care. Due to this diversification of services that began in the 1970s and 1980s, *total* coverage of services has not declined. It is also much higher than suggested by user rates of just institutional care and SAD.

It is noteworthy that Swedish services for older persons are *not* (after poor relief legislation was abolished in 1956) means-tested: Assessments only consider the need and services are used by all social classes: Obituaries for upper-class persons frequently formulate thanks for good public services. Yet, fees for these services are graded both by income (not by property) and by the amount used (about 40% of the users get them for free, due to low income). For affluent people it can therefore be advantageous to find alternative solutions to their needs, usually in the market.

With this background of state involvement and interference with civil society one might expect weak voluntary organizations and little family care. Yet, quite the opposite is the case. In the 1700s and 1800s farmers started fire insurance funds, producer cooperatives, road maintenance associations etc., with or without official encouragement or dictates. Workers unionized, modern political parties emerged, people started consumer and housing cooperatives, religious dissenters organized and built their own churches, there were library associations and

educational efforts, associations for charitable work, garden associations, home owner associations and so on. The recent rural history, the transparency of public administrations and all these associations probably helped to create a high level of trust in others and in the authorities and a surprising willingness to pay taxes found in opinion surveys in the Nordic countries. Most of the above-mentioned associations are still active. They lobby and are important pressure groups, and can mobilize members when needed. Associations often collaborate with public administrations, local and national, and frequently receive more or less symbolic financial support.

A suitable example is the pensioner organizations, some thousand local ones united in a national federation. About 40% of older persons are members. Locally they run telephone chains for isolated or frail members and have other activities to enhance health, often with some municipal support (financial, a room for meetings etc.). This "supplements" the more robust and streamlined public services. Historically, voluntary organizations started programs which were later "taken over" by the authorities; public Home Help thus started as a voluntary activity by the Red Cross and women's organization in the 1940s. A related and more recent example is the monitoring of medical prescriptions for older persons, who often consume too many and unsuitable medicines including psychotropic drugs, with big local variations. Central directives to physicians to be more restrictive had little effect, but local activities by pensioner organizations to publish scary statistics on local consumption patterns and efforts to educate older persons - the consumers – was effective and created the right kind of publicity around the issue. The state then hurried to rule that all persons 75+ shall have a responsible doctor who monitors medicines.

Older persons are increasingly active in voluntary organizations, judging from repeated surveys 1992 – 2014 (Jegermalm& Sundström 2014, von Essen, Jegermalm& Svedberg 2015). Among persons 65-74 are 82% members of at least one organization, and 43% are active (rates go down after 75, but are still high for the 85+)(after Jegermalm& Sundström 2014). A stable 4 out of 10 Swedish adults 16-74 report activities in some association, but many of these are for sports and recreational activities etc. Surveys suggest that persons in need rarely receive support from a voluntary organization, at rates of maybe 2-3 % (Jegermalm& Sundström 2013, 2014).

The local and national authorities in the Nordic countries have agreements (Sweden 2009-10) with umbrella organizations of voluntary associations, in the hope of furthering more voluntary work. In Norway the ambitious plan is that 25% of long term care shall be provided this way; whether this is realistic remains to be seen. In Sweden many municipalities have set up clearing-houses, where

people willing to be voluntaries and people/organizations who want them can meet (*frivilligcentral*). There is little evidence on how successful they are.

Another background necessary to understand Sweden is the unusual demographic history of the Nordic countries. There were always rather many who never married or had children, at least since 1749 (start of population statistics). For example, about 20% of the women 1749-1900 never had children, and many lost the ones they had before they (the mothers) were old and died. These patterns have changed for the better quite recently, with more people beginning to marry and have children in the 1940s. Today just some 12% of older persons are childless. Older persons increasingly live with a partner (and only a partner) and marriages/unions last ever longer. It is therefore not surprising that we in fact see stability of family care or even an increase, in surveys from the 1950s and onwards. To some degree this may be a response to today's stricter needs assessments in the public services, but probably also (and more) simply reflects that more people *have* close family: partner, children etc. In 2009 a new law mandates municipalities to offer support to family carers, although surveys suggest that most carers do neither need nor want support for themselves: They want good services for the person they care for. (There are since 1956 no family obligations, except for spouses.)

An important aspect of voluntary work and informal (family) care is the relationship between them. It is often assumed that they "compete": If you do this one, you are unlikely to do the other. In fact, many people do *both*, as found in Swedish surveys (Jegermalm& Sundström 2014). To some degree they mobilize each other. Many voluntaries are recruited by family members or other persons in their social network, and quite a few are carers themselves. Conversely, it is for example common that carers for a demented person (often a partner) are members of an Alzheimer association and/or a family care association, and do work in that organization also, during and after the care commitment. Surveys show high willingness to do (hypothetically at least) voluntary work, among both younger and older people, but most do not want to follow strict schedules in these activities.

We may sum up the above in the simple statement that the large majority of older persons who need some kind of help get it from their family, neighbours, and friends. When needs get more substantial, they also use public services – most users get help from their family -, and maybe also some support from a voluntary organization. The fact that most families and voluntaries provide rather small amounts of help does not mean that it is unimportant (that is a bureaucratic perspective), it may in practice make all the difference for the recipient. It rather reflects that most people, young or old, in need have on average rather small needs. Extensive needs of care (other "smaller" needs may be more prolonged)

usually emerge during a rather brief (and briefer for men than for women) period at the end of life, when at least half of older Swedes move to an institution, where they spend ever shorter sojourns. Most families seem to continue their attention, but in a different way, also in these settings. Pensioner organizations frequently do voluntary work there as well, but usually insufficient for the needs.

Market alternatives were common half a century ago, when many older persons lived in sub-standard housing, and needed help with laundry, cleaning, and other practical issues. We know this thanks to a representative survey to older persons done by the government in 1954, after scandals had erupted in institutional care, forcing the authorities to do something. This lead to a strong recommendation to municipalities to primarily provide Home Help, a policy that was supported by government subsidies for several years. With the new Home Help and rising standards of housing private services vanished, but have now reappeared. Tax subsidies (RUT) introduced in 2007makes it relatively inexpensive (regardless of age) to buy market services with household chores, including help to cut grass etc. (many older persons have a private home), and especially for persons with middle-range incomes or more. This is now common among older persons, often in combination with public services like Home Help and transportation services, and/or help from family. Use increases with age, with 7% users among people 65 years old, and 18% among 90 year olds (www.scb.se).

In summary, the typical Swedish (Nordic) panorama is that older persons in need draw on a number of overlapping sources of support, help and care. It also seems that many prefer not to be dependent on just one provider.

References

Jegermalm, M. y G. Sundström. 2013. "Carers in Sweden: The support they receive and the support they desire", *Journal of Care Services Management*, 7(1): 17-25.

Jegermalm, M. y G. Sundström. 2014. *Ideella insatser för och av äldre: En lösning på äldreomsorgens utmaningar?* [Voluntary work for and by older persons: A solution to the challenges in care for older persons?]. Stockholm: Forum för idéburna organisationer med social inriktning.

Jegermalm, M.; B. Malmberg y G. Sundström. 2014, *Anhöriga äldre angår alla! [Olderfamily is everybody'sconcern!]*. Kalmar: Nationellt kompetenscentrum anhöriga (enlace).

von Essen, J.; M. Jegermalm, y L. Svedberg. 2015. *Folk irörelse: medborgerligtengagemang 1992-2014* [People on the Move – Civic Involvement 1992-2014]. Stockholm: Ersta Sköndal Högskola.Arbetsrapport 85.

With studies in Sociology and a doctorate in Social Work, Gerdt Sundström began to work at the Institute of Gerontology in 1985. There he does teaching and research, as he did before at the School of Social Work in Stockholm. His main area of interest is formal and informal care and the balance between what the state and the family are doing for older people. In recent years, he develops several research lines, especially the Cooperation between family care and public services —or lack of it— and market alternatives are analyzed in international comparisons. This has entailed collaboration with researchers in the Nordic countries and, among other countries, in England, France, Israel, Japan, The United States and also Spain. Gerdt Sundström believes it is instructive to juxtapose Sweden with Spain, which has a different social structure but is now expanding her social services very rapidly and has good data on them and the population. In this vein, he has also studied religiosity among older Spaniards and Swedes, perceived loneliness — much higher in Spain — and shifts in family structure.

[Fuente: https://ju.se/en/personinfo.html?id=627]