

COMMUNITY-BASED ATTENDANT SERVICES IN SWEDEN: DESCRIPTION AND REFLECTIONS

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Sweden is known the world over for its progressive social services policy, not the least in the area of disability. This reputation, however, often seems founded more on belief than on solid information. One of the reasons for the lack of factual information on Swedish efforts, in my opinion, can be found in the liberal use of normative descriptions in Swedish documents which the foreign reader might easily mistake for descriptions of the actual state of affairs. Another source of misleading information is due to enthusiastic eyewitness reports by foreign visitors who intend to use the Swedish example for the purpose of influencing policy makers in their home country. Finally, most visitors are able-bodied. They face the problem of assessing service delivery programs of which neither they nor their Swedish hosts have direct experience. Such information impedes evaluation, comparative analysis and, ultimately, assessment of the transferability of Swedish policy instruments to other countries.

The present article's purpose is to give an account of Swedish community-based attendant services at home, at school, and at work. As a complement to the description of the various programs some analysis and reflections are offered. These are based on the author's experience as a consumer of Swedish attendant care services. A brief outline of a suggested consumer-directed home care attendant system concludes the article. But first, by way of introduction, a few facts and figures on the situation of the disabled minority in Sweden.

Second-Class Citizens Despite Government Efforts

Sweden is not the promised land for its able-bodied and especially not for its disabled population. Less than 20 per cent of all physically disabled aged 16-64 are gainfully employed compared to 68 per cent of the total population in that age bracket. Only 4 per cent have

attended college as opposed to the national average of 15 per cent. Physically disabled are four times as likely to be socially isolated as the general population. Recent government statistics¹ show that the disabled are worse off in practically all aspects of life. They are conspicuously absent in leadership positions in politics, administration, business, the media, and even their own organizations.²

It is evident from these figures that, though the disabled in Sweden have achieved better living conditions than the disabled in many other countries, they still have a long way to go for "full participation and equality." A key strategic area for achieving the integration of disabled persons is in the development of community-based attendant services, to which the article below is devoted.

Assistance at Work

The Swedish National Board of Labor and its local offices throughout the country have a range of policy instruments at their disposal intended to improve the disabled minority's chances in the labor market. Programs include medical and vocational rehabilitation, incentives to the employer in the form of wage subsidies, legal measures to force employers to hire disabled workers (very rarely used), grants for technical aids and modification of cars and work places. A relatively new addition to this list consists of the provision of personal assistance to disabled employees. Assistance may be in the form of practical help in getting in and out of the car, to the toilet, for arranging heavy items, and other help which enables the employee to perform his work. Blind persons can get readers, deaf workers are entitled under the program to interpreters in sign language. The person assisting may be a janitor, a colleague or somebody from outside the firm.

The program is financed by the National Board of Labor through tax funds. The employer presently receives a maximum of \$3,400 per year for his expenses in providing assistance. The amount corresponds very roughly to 25 per cent of an average full-time salary. Thus, the employer is not reimbursed for assistance to persons who need more than 2-3 hours a day.

This program is still new and limited. At present about 900 disabled employees participate.

Assistance at School

In order for disabled children and youth to attend their regular neighborhood schools it takes architecturally accessible structures and personal assistance. As to architecture, since 1967 the law requires all new schools to be built accessible. Most schools erected before that date have remained inaccessible. In Stockholm, for example, 60 per cent of all primary and secondary schools are inaccessible. The rest are partially or fully accessible.

Since 1965, practical assistance is provided to disabled children and youth of school age. Under the program an assistant may accompany the student on the way to school, help him/her to the toilet or during lunch or take notes. Blind students get readers. Deaf children qualify for assistants trained in sign language. A disabled student may have his own individual assistant or share one with other students, depending on the extent of the disability. Twenty per cent of all program participants receive help during the whole school day. About 65 per cent of the disabled children and youth have a physical disability, 8 per cent a sight and 5 per cent a hearing impairment. Eight per cent have psychological difficulties, and the rest are afflicted with epilepsy, minimum brain damage, autism, and social adjustment problems.³

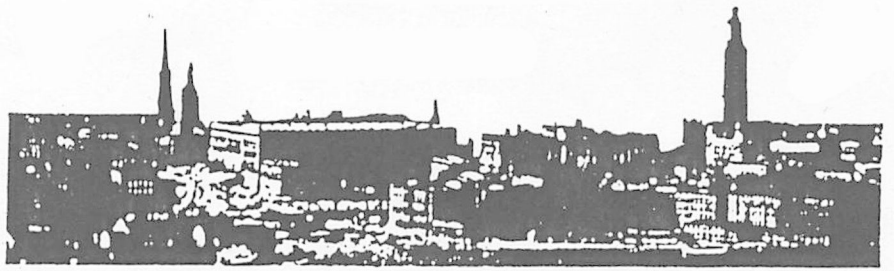
To be an assistant requires no special

training. About 80 per cent are under the age of 30. Many are just a few years older than the secondary students they are working for. Most assistants are housewives. The gross pay is presently \$750 a month. Assistants are employed by the school and students cannot choose who will work for them. The program's costs are divided between local government and state with the state contributing 40 per cent. In fiscal 1979/80 737 primary school students were covered by the program at a total cost of \$6.1 million. The cost for secondary school students was \$1.3 million.

There exists a similar program at the university level, the main difference being that all costs are borne by the state. Assistants are employed by the respective municipality in which the university is located. During 1978/79 costs were approximately \$500,000.⁴

To what extent is the Swedish school system integrated? The official policy is to start integration already at pre-school level. But in some communities the municipality instead of assigning a disabled child a place at the local kindergarten sends a babysitter to the child's home. A very rough indication of the extent of school integration is provided by a 1978 survey⁵ which found that 70 percent of all disabled students in 9th grade attended regular classes in their neighborhood schools. They were "individually integrated," according to the technical jargon. The rest was divided between those who attended special classes in local schools—they were "group integrated"—or went to one of the 12 state-run special schools which exist at the primary and secondary level. These institutions specialize in one particular disability and take children from all over Sweden. Their enrollment has increased over the years as more regular schools have been made accessible and more disabled students have assistants.

The type of school a disabled student attends and whether he/she has an assistant depends to a large degree on the respective municipality. As mentioned earlier, 40 percent of the program costs are covered by the state. Primary education is compulsory in Sweden, but not



secondary. Thus, for students at the secondary level the local government is not obliged to provide assistants. Instead many municipalities are quick to refer a disabled secondary student to one of the special state schools where all the costs including assistants are borne by the state—even if this necessitates a move to another part of the country. The argument used by local school administrators is often that special schools have much more resources. The organizations of the disabled, however, maintain that the social training among able-bodied peers in the regular neighborhood classroom can be more important in the long run than, say, the best physical therapy.

While it is widely recognized that many disabled students could not attend regular classes without practical help from their assistants, the program is not without critics. Some schools consider assistants as substitute teachers; disabled students with special needs might receive less individual instruction, if they have an assistant. Also, assistants will often do a task for the student instead of aiding the child in doing the work himself. The distinction is difficult to see and to maintain for untrained personnel. Having an assistant may reduce the student's and the school's incentive for using technical aids. Over-protective assistants may isolate the disabled student from his classmates—in short, assistants may present a hindrance to the disabled child's development towards more independence.

Often the disabled student receives the necessary practical assistance from classmates. This solution, however, as desirable it may be, cannot be relied upon in all instances and at all times. As pointed out by teachers,⁶ the novelty of helping the disabled classmate may wear off and leave the disabled child in humiliating dependency.

It has been argued that the presence of an assistant emphasizes the disabled child's special status which in itself constitutes a segregating element. A possible solution might be to have the assistant tied not to the disabled student but to the whole class. Then he/she could also assist other students who might need help, such as immigrant children.

Attendant Services at Home

Swedish home care attendant services are integrated with other social services under the responsibility of local governments. The state contributes 35 per cent of the cost. Decisions on type and quality of service rest with the municipality. As a consequence there are wide regional variations in service delivery depending on local government finances and political majority in the city council. Basically, home help attendants can be provided to the general population in the following three situations.

- Families with children when the parents are sick or otherwise unable to care for their children. While the service is intended for shorter periods, disabled persons with children can get this help on a regular basis in those communities where the program exists.
- Sick children who normally attend day care or nursery school in order to enable their parents to get to work. Again, this service is temporary and usually very hard to get, but parents with disabled children can receive regular help. The service may be available several hours a week, an evening or a weekend. Only a few communities have this help. More commonly parents receive a salary from the city for their work with a disabled child.
- Disabled and elderly persons who need practical assistance in their daily lives.

The programs are administered by the municipal social service at the neighborhood level. To give an example for the organization, the city of Stockholm is divided into 18 social service districts. Each district serves 20 to 30 thousand inhabitants. Each district, in turn, consists of one to two dozen subdistricts. The various social services including attendant care are coordinated by social workers at the district office who dispatch attendants to consumers in their respective subdistricts. In this way social workers who also are supposed to make periodic home visits and attendants gain familiarity with their clientele.

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Home help for the disabled and elderly might consist of assistance in getting up, getting dressed, personal hygiene, cooking, shopping, cleaning, taking walks, and so on. The need is assessed by a social worker at the district office. There are altogether 350,000 persons in Sweden who receive the service, i.e. 4.5 per cent of the total population of 8 million.⁷ Twenty to twenty-five per cent of all persons over the age of 65 are users. The average number of hours per person is 2.6 a week with wide variations, from 2 hours every other week for cleaning up to several hours a day. Yet more than 30 to 40 hours a week are rare. In some communities home attendants are not available after office hours and during weekends.

Where disability is accompanied by chronic medical conditions or where help is required during the night, the responsibility for that part of the service rests with the counties. In most counties the care is delivered by the regular municipal home help staff—complemented by a visiting nurse where necessary—and the cost is borne by the county. In some places the county sends its own staff, usually nurses' aides, to the home for the more medically oriented tasks while municipal home help attendants take care of the nonmedical chores. The solution seems awkward. Besides the obvious difficulties in defining tasks and coordinating the two agencies' staff, consumers complain about the constant flow of different people through their home disturbing their privacy. In other counties cash payments are made directly to consumers who then can employ relatives, neighbors, or others.

Between 80–90% of the attendants are female. They are usually middle-aged housewives who choose working hours to suit their families. Four per cent are full-time, 51 per cent part-time employed, the remaining 45 per cent work on an hourly basis. Fifteen per cent of all home help attendants are relatives who are employed by the city to work for their old or disabled spouses, parents or children. Attendants are commonly called "home samaritans" and their pay is accordingly the lowest municipal wage, presently \$5.50 per hour. Of the 70,000 attendants who worked in Sweden during 1980 about 30 per cent had received some training, usually a two-week course.

The cost of the service to users varies widely among municipalities. In some places the service is free. In others, fees are charged per hour with a maximum

monthly amount. The ceiling is mean-tested and may go up to \$400 in some cities. In other schemes all users pay the same flat fee regardless of the number of hours of service received. Disabled persons under the age of 65 are entitled to a monthly non-taxable allowance from the National Insurance. The amount depends on functional disability and the present maximum is about \$150. The payment is intended as a compensation for disability-related expenditures and includes attendant care.

One of the expressed aims of assisting disabled and elderly persons in their home is to reduce the demand for costly institutional care. A place on a long-term ward today costs approximately \$75 per diem excluding food and medically related costs. The cost of one hour home help to the employer is presently \$8. In order to make the two alternatives, home care and institutional care, comparable an average rent of approximately \$170 a month or \$6 per day for the apartment has to be taken into account. Compared to the most expensive alternative, then, it pays to provide home help as long as the need does not exceed 8 hours a day. This admittedly rough calculation nevertheless reflects some of the economics involved. Administrators are quick to point out that it is a person's whole life situation and not economic considerations which will decide where a particular individual will end up living. The irony is, however, that many more disabled—among them people in their twenties—as well as elderly people could leave hospital wards and other costly institutions, if planners would follow the economic criterion.

The number of persons put up in hospital wards who could live in their own home with several hours assistance a day has been estimated at 7000 for Sweden.⁸ There are several reasons for this obvious waste of human and monetary capital. Home help is paid by the city, hospital care by the county. Politicians at the local level are not willing to risk their career by suggesting a raise in local taxes to finance a larger home help program—a program which would save money for the county. Also, many persons cannot leave institutions because of the shortage of accessible housing. A recent government investigation suggested special subsidies for the installation of elevators in old apartment houses when they are renovated.⁹ What is needed then is a higher awareness of the gains and losses to society as a whole and more flexible instruments of revenue sharing between the various levels of government.

Areas of Conflict in the Swedish Home Attendant Care System

We now turn to some of the conflicts between the user and the home help organization. First, there is the question of attendant training. Both the organizations of the disabled and the municipal employees' union push more education. The disabled do this because they expect better quality service. The union does it because of the higher status and, ultimately, better pay (though at present more training is not rewarded by better wages). These organizations' efforts in this direction may be self-defeating in the long run. Given tight municipal budgets, higher wages for the attendants mean less hours of service for the disabled. Whether the loss in hours would be offset by higher quality service remains to be seen. Many attendant care consumers would agree that the less health care-related training attendants have—not to speak of courses in disability psychology offered by some social service offices—the easier it is for the consumer to direct his or her attendants. If somebody is to be trained, it should be the user of attendant services. To motivate and direct another person takes some psychological and educational skills which have to be learned. Besides, the turnover rate among attendants is much higher than among users which makes an investment in user's training more meaningful.

Another conflict area is the following issue. The home is an integral part of one's life style and expression of one's personality. But at the same time it is a work place for several persons who have the right to good working conditions. It is common that a representative from the district office inspects the user's home in order to determine whether conditions conform to requirements which have been established in negotiations between employers, i.e. the municipality, and union. Users and the organizations of the disabled have no right to participate in these negotiations. Should a user refuse to have his/her home conform to these requirements, the social service office may be forced by the unions to discontinue serving this particular user.

A related issue is the attendant's duty to report to the office problems that he/she might observe in the user's home. This can be the need for a particular technical aid, medical problems or alcoholism.

The potential for this type of conflict between user and service organization seems largest in the semi-institutional

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arrangement. This is commonly referred to abroad as Fokus housing. In Sweden it is usually called "service apartment" or "koncentrat." Briefly, a "koncentrat" consists of 6 to 15 specially designed apartments which are interspersed throughout an apartment building complex of some 100 to 200 units. The special apartments are owned by the social service office and rented out with a regular rental agreement to disabled persons who might live by themselves or with their families. From a staff room on the premises attendants are on call 24 hours a day. There have been instances where the staff in such a "koncentrat" have been ordered by the social service office to prepare reports on the residents for the purpose of making the operations more efficient. Residents were not informed. The dossiers included information not only on daily service needs but also on personal habits and an assessment of individual residents' personality.¹⁰

To sum it up, I see in the move towards professionalization and institutionalization of Swedish attendant services the danger of over-protection, social control, and limitation of the individual's initiative—precisely the opposite of help for self-help.

Reflections on the Optimal Home Care Attendant System

The Swedish attendant care system is intended to contribute to the integration of the disabled. At the same time it is characterized by centralized decision making without consumer input. The contradiction here—mainstreaming the disabled without granting them control over important aspects of their daily lives—has largely gone unnoticed in the Swedish debate. Concepts such as de-professionalization and consumerism have not yet become part of the ideological equipment of the disabled movement. In contrast to Swedish home care attendant schemes a truly user-directed solution would entail hiring, training, scheduling, and firing of attendants by the disabled themselves. These activities require skills which can be acquired by most people, if necessary through courses directed by their peers.¹¹

Apart from the lack of consumer con-

trol Swedish attendant care schemes have the disadvantage of limiting the geographical mobility of the severely disabled. In many communities the only alternative for persons who need extensive assistance and live by themselves are the above mentioned Fokus or koncentrat apartments, because the social service offices cannot provide individual attendant care at odd hours outside these settings on a long term basis. As the term "koncentrat" implies, the solution is based on geographical clustering and a limited number of locations. Thus, the arrangement cannot serve people who are unable or unwilling to relocate. This brings up an important point. If the disabled are to fully participate in society, they have to have the same degrees of freedom in the housing market as the rest of the population. This requires attendant services which follow the user—not the other way round. The Fokus solution, which has also received favorable attention outside Sweden, is thus incompatible with the aim of mainstreaming the disabled.

One of the requirements of a user-directed attendant scheme as outlined above is that the consumer also handles the money. A financing plan in line with the concepts of consumer control and flexibility is a tax-funded national attendant care insurance. In contrast to the Swedish solution where the service is paid for by local governments' general taxes and matching funds from the national government, the insurance plan would eliminate the regional inequalities in service delivery present in the Swedish scheme. (Incidentally, a block grant system to regional governments is also susceptible to such inequalities.) Since under the insurance plan funds are tied to the user, services are not dependent on local government finances and preferences. The amount paid to the user should ideally not only take into account the user's level of functional disability and the local cost of labor but also the individual's whole life situation, i.e. attendant needs at home, at school, work, and leisure.

Conceptually, the user-directed system and the present Swedish attendant scheme can be considered the two extreme points along a continuum. Various intermediate solutions seem possi-

ble consisting of different allocations of responsibilities (such as advertizing, interviewing, hiring, etc.) among user and social service agency. As an individual acquires more skills and confidence, he/she can gradually take over more functions with the result of more independence and pride to the user and lower costs to the social service agency.

¹National Central Bureau of Statistics, *Disability: Participation and Equality?*, Living Conditions Report No 25, Stockholm, 1981.

²Dennis Wyant, "Sweden, Land of Opportunity for Disabled People," *Disabled USA*, Vol 2, No 8, 1979 and Lex and Joyce Frieden in *Living Independently: Three Views of the European Experience with Implications for the United States*, World Rehabilitation Fund, New York, 1981 made the same observation.

³Statistics on school assistants and their users from Integrationsutredning, *Personlig assistans för handikappade*, Statens Offentliga Uträdningar SOU:82, Stockholm, 1981, p. 170.

⁴*ibid.*

⁵Brattgard, S.O., Hilmerson, G., *Rörelsehindrede elever i årskurs 9*, Department of Handicap Research Report No. 62, Gothenburg, 1978.

⁶Integrationsutredning, *op. cit.*, p. 56.

⁷National Central Bureau of Statistics, *Statistical Report SCB S 1980:24*, Stockholm, 1980.

⁸"Boendeservice i varje kommun," *Svensk handikapptidskrift*, Vol 58, No 9-10, Oct. 1981, p. 21.

⁹Stadsförnyelsekommittén, *Stadsförnyelse och bostadsförbättring*, Bostadsdepartementet SOU 1981:99, Stockholm, 1981, p. 170.

¹⁰One such incident at Fältöversten, one of Stockholm's koncentrats, received national attention when the Office of the Parliamentary Ombudsman (Justice ombudsman) ruled that Stockholm's social service office had violated the residents' right for privacy and integrity.

¹¹Such training for consumers is provided by most independent living programs in the US (see Gerben DeJong and Janice Hughes, *Report of the Sturbridge Conference on Independent Living Services, September 30-October 1, 1980*, Medical Rehabilitation Research and Training Center, Tufts-New England Medical Center, Boston, Mass., 1981.)