Disability Policy in Sweden

Policies Concerning Assistive Technology and Home Modification Services

Margareta Lilja, *Karolinska Institutet, Stockholm, Sweden*
Ingela Månsson, *The Swedish Handicap Institute, Stockholm, Sweden*
Leif Jahlenius, *The City Planning Administration, Stockholm, Sweden*
Maryanne Sacco-Peterson, *Karolinska Institutet, Stockholm, Sweden*

This article describes policy concerning provision of services to persons with disabilities in Sweden. The Swedish welfare system provides general support for society as a whole, which is supplemented by specific support for persons with special needs. This philosophy has guided the way Sweden has built public service systems. The authors describe the range of accessible services for persons with disabilities, including the system of delivery for assistive technology and housing modifications. Strengths and weaknesses in Swedish policy related to decentralization, responsibility, equality, and cost are also discussed.

Assistive technology (AT) and environmental modifications have the potential to facilitate the quality of life of persons with disabilities in terms of activities of daily living and participation in society. This article describes policy features and issues surrounding the provision of AT and environmental modifications to individuals with disabilities in Sweden. It also provides a comparison on an international level of sociopolitical philosophy, policy, and service delivery systems.

Health policies of various European countries are individual reflections of each nation's political and cultural histories. In Sweden, as in many other countries, policy concerning people with disabilities is expressed in terms of integration, full participation, and equality (Hugman, 1996; Swedish Institute, 1999). The basic philosophy upon which the Swedish welfare system is grounded is that of providing a system of general support for society and supplementing it with individualized support for persons with disabilities. This philosophy has guided the way Sweden has built its public service systems. In 2000, the Swedish Parliament also adopted a national policy for elderly persons and individuals with disabilities (Ministry of Health and Social Affairs, 2000). This policy states that people with disabilities should have the same opportunities and the same obligations as everyone else in society and be offered equal resources, regardless of where they live.

There is a lack of reliable information concerning the number of people in Sweden who have disabilities. To a large extent, this is due to the difficulty in defining what constitutes a disability. Furthermore, it is difficult to establish a clear picture of the situation because individuals may have several different types of—and varying degrees of—disability. Data from several statistical surveys may be used, however, to construct an overview of needs in this area. Physical disabilities, which are common, often are related to age. For people in Sweden between the ages of 16 and 84 years, it is estimated that 12.6% have mobility problems and approximately 1.2% are dependent on a wheelchair for mobility. At least 14.7% of individuals in this age group are believed to be dependent on a hearing aid to communicate with others. Visual impairment is also a major problem, and 1.3% are estimated to have sufficiently impaired vision to cause problems in daily tasks such as reading a newspaper. Approximately 170,000 people in Sweden are estimated to have various forms of dementia.

One important factor in regards to the development of disability policy in Sweden has been the movement for people with disabilities. At a national level, more than 70 organizations represent specific disability groups, with some 2,000 local associations existing nationwide. These organizations are also run by and highly represented by people with functional disabilities. Approximately 40 of these organizations receive financial backing from the state, county councils, and local authorities for their activities as political interest groups, that is, their work involving publicity, opinion formation, and roles as reference groups for issues important to individuals with disabilities (Swedish Institute, 2000).

In Sweden, a basic principle of the national policy concerning elderly persons and individuals with disabilities is that

the needs of the individual must always be paramount in designing the services provided. This means that services such as AT and home modifications are based on need rather than population demographics. The implementation of the policy is supported by a tax system to which all taxpayers contribute, for the good of all, according to individual financial capacity. With an eye toward the principles of an egalitarian society, Swedish government agencies have distributed funds with the objective of leveling out differences in living conditions (Ministry of Health and Social Affairs, 2000; Swedish Institute, 2000).

Swedish health services for persons with disabilities are organized in three hierarchical political and administrative levels—the state at a national level, the county council at a regional level, and the local authority at the municipality level. The National Board of Health and Welfare (*Socialstyrelsen*) is the state's central advisory and supervisory agency and is responsible for health-care and social services. Another government agency engaged in evaluation work is the Swedish Council of Technology Assessment in Health Care (SBU). The SBU contributes toward the efficient utilization of the resources allocated to the health services by evaluating both new and established methods from medical, social, and ethical perspectives. County councils have primary responsibility for health care provided in hospitals and primary health-care centers, and local authorities have responsibility for education, housing, child day care, social services, and nursing homes (Swedish Institute, 1999, 2000).

In Sweden, care services for older individuals and persons with disabilities are regulated by framework laws (The Social Service Act, The Health and Medical Service Act, and the Act Concerning Support and Service for Persons with Certain Functional Impairments). These laws specify the framework and objectives of care and service provisions, but they also afford the county councils and local authorities ample freedom to interpret the law and implement these services according to their own specific guidelines (Hedin, 1993; Swedish Institute, 2000). The trend over the past decade has been toward greater decentralization of responsibility. State influence has decreased, and greater responsibility has been laid on the counties and local authorities. This has resulted in the establishment of private initiatives in both medical and social services.

The divisions of responsibility in Swedish governments, and the drift toward private initiatives, have affected the situation for persons with disabilities. The great freedom that county councils and local authorities have in deciding the quality and nature of what practical measures will be undertaken has led to national differences in the provision of services. Furthermore, the number of different actors in the organizations that provide services influences the distribution of resources, sometimes leading to overlapping or missing services. On the other hand, the private initiatives have put pressure on the county councils and local authorities to work in a more service-oriented and efficient manner (Johansson, 1997; Swedish Institute, 2000; Thorslund, Bergmark, & Parker, 1997).

General Accessibility Services for Individuals with Disabilities

As in many industrialized countries, Sweden has developed an extensive system for providing social services and medical care. This system meets a wide spectrum of needs and provides such services as personal care, domestic assistance, transportation services, day care for the young and the elderly, total institutional care, and AT and home modifications.

In the medical sphere, the system provides subsidies for (a) doctors' visits, (b) prescription drugs, and (c) medical care at home and in a hospital. For instance, within the county councils' habilitation services for children with disabilities, resources have been developed for assessment; treatment; and the provision of physical, occupational, and speech therapies.

By law, children with functional impairments must be given places in general education schools. Specially trained personnel provide support and supervision for both parents and school staff members.

Persons under the age of 65 who have extensive functional disabilities have the right to personal assistance that is free of charge. Persons with disabilities are also given opportunities to study and improve their circumstances or to find work in the open market; when this is not possible, they are assisted in creating alternative employment opportunities. Every local authority has an organized home-help service for persons in their jurisdiction who are elderly and/or have disabilities. This help is mainly delivered at home and includes personal care, house cleaning, cooking, and shopping. Home help staff persons may even perform such functions as helping the person take a walk. Until the age of 65, persons with functional impairments and parents of children with functional impairments can obtain state aid for purchasing and adapting services related to one's own care. As of 2000, approximately 15,000 individuals had utilized this state aid (Hedin, 1993; Swedish Institute, 2000).

In order to meet the transportation needs of elderly people and persons with disabilities, Sweden has constructed a municipal transportation system that entitles these persons to travel by taxi or specially adapted vehicles. This right is often restricted to a certain number of journeys or by a particular distance traveled. The cost to the consumer for this service is no more than what other travelers in the community have to pay for using public transportation. Fares, however, vary considerably among different local authority areas, and this may impose a serious financial strain on the individual (Hedin, 1993; Swedish Institute, 2000).

We will now provide a more comprehensive description of AT and home modification services, because both have a great impact on other services and on the possibilities for individuals who have been marginalized to participate in society.

AT and Environmental Modifications

As mentioned earlier, disability policy in Sweden is based on the concepts of integration, full participation, and equality. These goals have also guided the way Sweden has built systems for providing AT and environmental modification services and for planning and constructing housing environments. An essential part of this service delivery system is information about existing services and how to obtain and use them. In Sweden, health-care personnel have the primary responsibility for providing this kind of information to consumers, although no laws or regulations guide the procedures. Another general principle that has guided the development of service provisions in Sweden is that of "professionalization," meaning that practical care should be carried out by professionally trained and qualified staff members (Swedish Institute, 2000).

Assistive Technology

In Sweden, AT is considered an integral part of health care, and it is prescribed, distributed, and financed through the auspices of the national health system. For the purposes of this article, we define AT as ranging from relatively low technology, such as a swivel spoon to enable eating, to more sophisticated technology, such as computers to enable communication (Smith, Bange, & Hall, 2000).

The Swedish Handicap Institute has a central role regarding AT and accessibility for people with disabilities. The Institute is run jointly by the Ministry of Health and Social Affairs, the Federation of Swedish County Councils, and the Swedish Association of Local Authorities. The Institute stimulates research and development, assesses and procures new AT, provides quality assurance, contributes knowledge and information, and carries out training (Swedish Handicap Institute, 2000b). The county councils have the main responsibility for providing medical-care services, including AT. Most counties have a Board for Assistive Devices that consists of elected officials, consumers, and civil servants. The Board guides and supervises activities concerning the provision and distribution of AT and also deals with policy issues and consumer problems that are of particular importance. Consumer groups are also active in bringing pressure for change and improvement in services that provide AT, such as issues surrounding what products should be defined as assistive devices (Swedish Handicap Institute, 2000a).

Provision of AT should be based solely on need, regardless of the person's age, economic status, or place of residence (Ministry of Health and Social Affairs, 2000; Swedish Institute, 2000). In general, occupational therapists, physical therapists, and nurses prescribe AT in their daily work, and most prescriptions are carried out in primary health-care settings as a part of rehabilitation services. In most cases, the need for devices and other services is discussed by the individual therapist and his or her client, and a joint decision is made. At the county council level, there are assistive technology centers that mainly provide specific AT devices, such as lifts, specialized wheelchairs, and computerized technology. Persons with visual impairments are treated in ophthalmology centers; individuals with auditory impairments are treated in audiology centers. Most of the orthopedic services are private and are contracted out by the county councils. Every county council or local authority has its own guidelines concerning provision of these services and decisions as to which products should be defined as AT and prescribed to the client (Swedish Handicap Institute, 2000a).

Another important aspect related to policies of AT provision is the issue of economics. The strong autonomy of the county councils and the local authorities in Sweden have led to difficulties in determining the total cost for AT, but the latest figures (1996) showed that this was approximately 6 million Swedish kronor (approximately $600,000 in U.S. dollars).

Home Modifications

Every local authority in Sweden is obliged by law to provide a housing modification grant to people with disabilities who live within the authority's catchment area and are in need of some adaptation or modification to their dwelling. The grant is available for persons with all types of permanent disabling conditions resulting in, for example, impaired vision or mobility, allergies, dementia, or learning impairments. Funding is provided irrespective of the financial situation of the applicant, and it is not dependent on a person's housing situation (i.e., rented versus owned apartment or house). All costs are covered for adaptations that are determined to be necessary for the elderly person or person with a disability to be able to perform everyday activities, such as entering and exiting, moving around in the home, and managing personal and domestic tasks (National Board of Housing, Building and Planning, 2000; Swedish Institute, 2000).

In general, two separate levels of government are responsible for implementing housing policies. Legislation and funding are state issues, whereas actual housing is the responsibility of the local authorities. Sweden has long-standing building regulations stating that everything being built or rebuilt should be accessible and usable for individuals with disabilities. This means that (a) all building interiors—and even the entire outside environment—should be accessible, and (b) all dwellings, even private homes, built since 1978 should be accessible in a way that allows for a person with a disability to visit the dwelling (Månsson, 1999; National Board of Housing, Building and Planning, 2000a).

The most common home modifications measures are usually minor in nature, such as leveling thresholds, adapting water faucets, or installing safety timers for cookers. Common extensive measures are rebuilding the bathroom and replacing the bathtub with a shower; installing automatic door openers, special toilets, leveling platforms, stair lifts, and ramps; improving the lighting; changing the surface material on walls or floors; and modifying the kitchen. In some cases, the adapta-

tion can be very extensive, such as one involving lifts and doorway extensions (National Board of Housing, Building and Planning, 2000b). The basis for determining what measures should be financed is a four-part assessment of the following:

1. the applicant's self-assessment of her or his problems and needs;
2. the occupational therapist's assessment of the applicant's disability and abilities and of ways to solve the functional problems;
3. the engineer's technical assessments of adaptive solutions for solving the problems of structural barriers; and
4. examination of legal guidelines concerning how the grant may be used.

How the adaptation should be done and what products should be chosen is a cooperative decision made by the applicant, the occupational therapist, the engineer, and legislators. The main guideline, of course, is that the modification and assistive products improve the applicant's functioning (National Board of Housing, Building and Planning, 2000a).

Resource Allocation Policies

In the 1950s, when the Swedish policy of integration and "normalization" for persons with disabilities was introduced, another major policy was formulated. This policy stated that a person with some disability should not bear the additional costs of reducing environmental barriers that restricted his or her performance in activities of daily life. As a result, both AT and home modifications are publicly funded. The county councils and local authorities are responsible for handling the resources in relation to general planning and distribution issues (Swedish Handicap Institute, 1994; 2000b).

In general, people with disabilities in Sweden have access to AT—including assessment, training, repair, and maintenance—that is either free of charge or provided at a negligible cost. AT is financed by taxes, usually through the counties. Since 1992, AT for elderly people or individuals with disabilities living in nursing homes has been funded by the local authorities (Swedish Handicap Institute, 2000a).

As early as 1959, a special housing modification grant was introduced in Sweden. The aim of this grant was to allow people with disabilities to be able to live as independently as possible in regular dwellings and residential areas. Persons who received the grant were able to finance necessary environmental modifications that were in line with building regulations. This made the choice of a permanent living place possible for individuals with disabilities (Ministry of Health and Social Affairs, 1992; National Board of Housing, Building and Planning, 2000a).

Local authorities decide whether a grant application should be approved or rejected and are responsible for handling the costs of the grant. There are, of course, limitations regarding how the grant can be used. The measures to be funded should be necessary, not just convenient. The measures financed by the grant should become a permanent structure on the building property and not something the individual could take with him or her when he or she moved. The grant cannot be used to cover ordinary building maintenance or problems due to faulty building construction, such as moisture damage. If there are products on the market with an identical function, the least expensive one will be selected. In terms of building materials, the grant covers only standard types. If applicants want something more expensive, they must cover the additional costs themselves (National Board of Housing, Building and Planning, 2000a).

The number of applications for these grants has increased every year. Currently, approximately 60,000 dwellings in Sweden are modified each year, and the cost is approximately 7 million Swedish kronor ($700,000 in U.S. dollars). About 80% of the grants are given to people with mobility impairments, 15% are given to people with memory loss or dementia, and 5% are given to other groups, such as people with impaired vision, allergies, or developmental disabilities. Approximately 85% of the people who receive these grants are 65 years of age or older (National Board of Housing, Building and Planning, 2000b).

Discussion

The greatest strengths of the Swedish health-care delivery system for the elderly and/or persons with disabilities are (a) national policy is clearly stated and supported by legislation and (b) there is political consensus concerning the policy. The delivery system encompasses all residents, regardless of the cause of their disability or their financial status. Both AT and home modifications are considered essential elements of health care and important for providing opportunities for persons with disabilities to participate in society.

There are weaknesses in the Swedish services system, however, that have had an impact on the services provided. Sweden is a highly industrialized country with a small population of approximately 8.9 million inhabitants. As the number of elderly people in the population increases, there is a growing concern about society's ability to cope with their needs at a time of restricted national economic resources. These circumstances are leading to an increasing gap between needs and resources. In Sweden there has been ongoing discussion about shifting some of the costs from society as a whole to the individual user in the form of increasing the small fees some county councils and local authorities require and possibly reducing subsidies. In the future, these policy discussions about resources, allocation, and costs will influence the provision of AT and home modifications. It thus is important to study costs, benefits, and the impact of these services. According to a recent study of the costs and benefits of AT devices and housing

modifications for elderly people in Sweden 1 year after an acute stroke, Gosman-Hedström (2001) found that the cost for AT devices and housing modifications was actually only 2% of the total health-care cost.

For local authorities, the home modification grant has also become a necessity from an economical point of view. To be able to stay in their own homes is a strong desire of elderly people and those with disabilities (Gaunt & Lantz, 1996), and it is also a basic principle of the national policy for these populations (Ministry of Health and Social Affairs, 2000). A possible alternative for meeting this goal is building special housing, which is very expensive. The cost to the local authority for one person in special living is approximately 1,800 kronor ($180 in U.S. dollars) per day, which can be compared with the average modification grant of 15,000 kronor ($1,500 in U.S. dollars). This means that if the grant can be used to create an environment that allows a person to stay at home for an additional 2 weeks, there is a profit. Furthermore, in the health-care sector, hospitals and institutions have dramatically shortened inpatient treatment time and hospital stays. Much of today's rehabilitation and health care thus are performed in the home, and the housing modification grant and AT have, and will continue to have, important roles to play.

Integration, full participation, and *equality* are terms often used at all levels in the Swedish welfare system. Information about what kinds of services are available, and how to obtain them, is crucial for reaching these goals. Questions have been raised concerning whether the system in itself is equitable, sustainable, and accessible for all. If persons with disabilities are unaware of the existence of the services they are entitled to receive, they obviously would not be benefiting from them. As of this writing, general guidelines for how this information should be distributed do not exist. As a result, the persons who have power and influence over the process of accessibility play an important part in the provision of AT and home modifications. Who are these gatekeepers? A wide range of professionals are involved in the delivery of Swedish health services, including engineers, occupational and physical therapists, physicians, nurses, and speech therapists. One limitation of the system is that it is rather closed and users thus are often dependent upon the choices that professionals make. Swedish consumer groups have become very active and influential in bringing pressure for change and improvement of services. For instance, due to consumers' efforts, most AT devices are free of charge, and universal design has become an important consideration in building and construction. In order to implement a quality process for providing AT devices and home modifications, and also to ensure equitable distribution, user influence is necessary at both general and individual levels. However, when it comes to the individual decision-making process, the amount of user influence varies according to the personalities of the professionals and the users themselves.

As of this writing, users who are dissatisfied with services have very little legal recourse. For instance, decisions about AT cannot be formally appealed to a higher authority. The involvement of the individual user in the actual selection of devices is subject to continuous debate, and practices may vary even among centers in the same local authority. Organizations that represent people with disabilities have demanded increasing the user's own influence to a level where the user makes the final choice of a device. Dissatisfied home-modification-grant applicants can appeal the decision of the local authority to a court of justice. In 2001, 320 applicants appealed such decisions. The courts overturned the decision in 90 of these cases.

It is essential to remember the complex system of other services available in the Swedish welfare state when discussing AT and home modifications. Questions could be raised concerning the ideal balance among the use of devices, home modifications, home help, and personal assistance. Equally important as the balance of services, technology, and adaptations is the timing of various solutions. In some cases, such as preventative measures, technology needs to be introduced and the home environment modified before there is an obvious need. This way of viewing AT and home modifications as a part of public health could have an indirect impact on quality of life, the cost of health care, and the structure of the decision-making process. How the decision-making process is carried out depends on several things. For instance, the autonomy of local authorities in Sweden has led to many differences among municipalities in their development of care resources and service provision systems, although some services are compulsory and must meet particular state standards. On the other hand, the present developments are creating a public demand, and a market, for new producers of services and care. How this will affect the provision of AT, home modifications, and other services in the future is hard to say.

In the future, the main arena for service and care expansion will be home-based care. Furthermore, as the number of elderly people in Sweden increases, concern continues to grow over society's ability to cope with the increasing need for medical and social services. This in turn will lead to an increasing demand for universal design and home modifications. New AT methods and products will be developed, creating new possibilities for elderly individuals and persons with disabilities to be more enabled and supported in their daily life activities. This implies a need for a greater "decentralization" of skills and services to community-based health care and a need to increase available resources at the local level.

ABOUT THE AUTHORS

MARGARETA LILJA, Reg. OT, PhD, is an associate professor at the Karolinska Institutet, Division of Occupational Therapy. Her research interests include community-based practice and a focus on the abilities of elderly people and their needs and interests in relation to occupational performance in the home environment. **INGELA MÅNSSON** is an occupational therapist and project coordinator at the Department of Analysis and Development of Service Delivery in the Swedish Handicap Institute in Stockholm. **LEIF JAHLENIUS,** an architect, has worked in building and planning for people with disabilities at the Swedish Institute for the Handicapped since 1974 and

as head of the department for housing modification grants in Stockholm since 1989. He is an expert on general accessibility in society through building regulations and individual housing modifications. **MARYANNE SACCO-PETERSON,** MA, OTR, is an occupational therapist and a doctoral candidate in occupational therapy at the Karolinska Institutet in Stockholm. Her research interests are gerontology and the science of occupations. She is currently involved in transnational research that examines how different cultural environments, and the meanings persons place upon them, obstruct or enable older individuals' participation in daily activities. Address: Margareta Lilja, Neurotec, Occupational Therapy Division, Karolinska Institutet, S-141 83 Hudding, Sweden; e-mail: margareta.lilja@neurotec.ki.se

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