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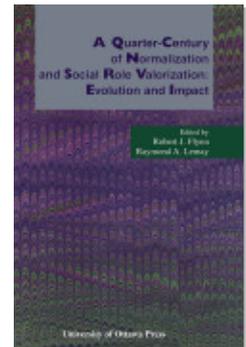
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The origin of the Normalization principle in Sweden and its impact on legislation today

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1 INTRODUCTION

In Scandinavia we can trace the origin of the Normalization principle back to the middle of the 20th century with the development of services for developmentally disabled persons. A government committee appointed in 1943 to investigate ways of making available means of employment and self-support developed a sociopolitical idea that became the guiding principle for their work. The idea was termed "the Normalization principle."

Thus, in Scandinavia, the Normalization principle expresses the sociopolitical proposition that the handicapped person has the right to participation in the broader society. It became a starting point for the development of services for handicapped persons that took place in the 1950s (Eriksson, 1985). Today, we can easily follow the tracks of this sociopolitical policy in a series of Acts of Parliament that have contributed to the realization of the Normalization principle from 1954, 1967, 1986, and 1994.

The Normalization principle as a sociopolitical concept and its consequences have been the subject of debate over the last 40 years. I believe that the Scandinavian concept has at times been thoroughly misused, which has led to discussions very foreign to the original formulations and intentions.

I will with this paper describe the background of the Swedish welfare state as the basis of the Normalization

principle and show how the principle is applied today in special legislation and welfare policy to promote equality and participation for the disabled.

2 THE BASIS OF THE SWEDISH WELFARE STATE AS THE ORIGIN OF THE NORMALIZATION PRINCIPLE

Contrary to a frequently stated view, Sweden did not shape its modern welfare system as a reaction to the economic crisis of the 1930s (Flora, 1986; Alestalo & Kuhnle, 1984). Since 1932, when the first minority social democratic government was formed, the dominant political parties became gradually favorable for state intervention and an increasing public responsibility in social policy, but there were large disagreements between and within parties on what should be done and how (Baldwin, 1990; Marklund, 1988; 1992).

After 1945 there was consensus among the major political parties concerning the major state welfare reforms with the industrial trade union movement actively forcing the issue (Olsson, 1990). The beliefs in social solidarity and equality values became the basis for the new social welfare programs (Baldwin, 1990). Although social democrats and trade unionists particularly concentrated on welfare for the working class and white-collar workers, the commitment to support people outside the workforce was also strong (Olsson, 1990). Under a comprehensive social welfare

system, marginal groups such as persons who are disabled, persons who are elderly, and children would receive quality service and support as a *right* and as a part of the provision for the overall welfare of the society. The Normalization principle thus developed during a period when discussions were taking place throughout society concerning the implementation of welfare policy. The ambition to create a welfare state required that society develop social and health services that would enable all citizens, even persons otherwise disabled, to live a good life. The Normalization principle was and continues to be an application of a philosophy of rights where the full benefits of citizenship are conferred upon all persons.

This perspective shows that the Normalization principle is not an invention—a nice man's idea—but an ideology that came out of a broadly based social consensus that had broad public support. However, the dominant parts of the welfare reforms were work-oriented and based on income compensation to the working population rather than cash payments to persons who were marginal because of poverty, unemployment, or disability (Ginsburg, 1992). Cash compensation for persons who are unemployed and relief for persons who are poor has played a decreasing role in social spending, while the costs for income transfers and labor market policies have increased constantly since 1945 (Marklund, 1992). This system is now undergoing change, and it is difficult to predict the future. But public support for the welfare system is still very strong in Sweden, and it seems that it will be difficult to destroy.

3 THE REALIZATION OF THE NORMALIZATION PRINCIPLE

During the 1960s the Normalization principle became a concept that, up to present day, has greatly influenced and characterized the work within the organizations responsible for services to the developmentally disabled in Sweden. This principle gained prominence during the period that led to the development of the 1967 Act for Services to the Mentally Retarded (Eriksson, 1985). As Nirje and Perrin have already pointed out, the Scandinavian version of the Normalization principle is the logical

extension of the welfare state's relationship to persons who are disabled. This view also implied a repudiation of institutional life and institutional systems of services. This version of the Normalization principle thereby expressed a sociopolitical position that starts with the right to participation in society.

Nirje has described the sort of life that should be possible for persons who are developmentally disabled. Nirje also places emphasis on self-determination. Both Perrin and Nirje have shown that it is the idea of self-determination that differentiates the Scandinavian model of Normalization from Wolfensberger's. Accepting individuals as they are, acknowledging differences, and providing opportunities and resources for personal growth based on individual preference eliminates some of the serious consequences of third-party decision making. The concept of Normalization is complex and in some senses contradictory. Facilitating and realizing participation and equality for persons with functional impairments must, in the full sense of these terms, involve all of society, including those who have no personal experience of functional impairments. One might suggest that implementing Normalization is a critical stage in the process of deepening democracy.

The universal social security system as it developed created a specific role for individual social services such as social assistance and special services for persons who are handicapped. Intervention by the state in these areas is seen as a recognition of structural tensions in modern society that are not always conducive to meeting the needs of the individual, and not because of abnormality or charity. Social security has lessened the role of stigma in connection with extra services based on need. This model, not only in theory but also in practice, was able to minimize the numbers of persons who have had to claim individually means-tested or needs-tested services.

Today the process of reform is guided by the principles of self-determination, availability, participation, and continuity. These principles emanate from the thesis of universal human equality (SOU, 1992:52, p. 8). The Normalization principle has more or less been replaced by the principle of self-determination. However, it is only to a minor extent that the general aspects of self-determination and the other above principles have been the subject of deliberations and positive action.

From the point of view of individuals with special needs, the Swedish model contains both positive and negative aspects. As a result of the efficient coverage of social security and relatively generous benefits, most individuals can rely on receiving the basics for daily living. However, the monolithic character of the system gives individuals very few alternatives, especially in those parts of the service system that are focused on services for people with special needs. The focus today is therefore to strengthen opportunities for independence and free choice for persons with severe disabilities.

4 LEGISLATION FOR SUPPORT AND SERVICES FOR PERSONS WITH CERTAIN DISABILITIES

Sweden is very much a society governed by law. Legislation continues to be used to promote welfare. During the last 20 years, several changes have taken place in the ways that support services are delivered. The emphasis on self-determination gives persons with disabilities opportunities to participate in society. This partly depends on how service providers succeed in expressing the intentions of their self-determined clients. With the proliferation of legislation, from the perspective of the individuals who are disabled, it can be increasingly difficult to know about their legal rights (Hollander, 1993).

In order to improve the possibilities for persons with disabilities to enjoy the basic opportunities of social participation, new legal rights are defined in three new pieces of legislation: the Act on Supports and Services for Persons With Certain Disabilities (LSS); the Social Services Act (SOL), which places certain obligations on service providers; and the Health and Medical Services Act (HSL). These changes are designed to develop and guarantee general accessibility and coverage for every social sector, with regard to matters affecting persons who are disabled. The challenge will be to find a balance between individualized and generalized measures that reflect a holistic view and are appropriate to the needs of persons who are disabled.

As a logical result of the definition of disability being framed in terms of the relationship between a

person and the environment, Sweden abolished certain specific pieces of legislation that proclaimed the special rights of persons with specific disabilities. Thus people with developmental disabilities and other people with severe disabilities should be treated the same as other citizens, even in the legal system. In accordance with efforts to integrate the various issues concerning the disabled, special sections have instead been inserted into other laws such as the Social Services Act, the Education Act, the Work Environment Act, and so on.

Today we still find exceptions to this general rule of not having specific legislation for special groups of people (Hollander, 1993). The Act on Special Services for Developmentally Disabled Persons was replaced in 1994 by the Special Act on Supports and Services for Persons With Certain Disabilities. The rationale for such special legislation is that people with severe disabilities need extra support and personal services because of their disabilities and because their living conditions are affected by their disabilities. In a special survey report, the Commission on Policies for the Disabled in Sweden showed that severely disabled persons were disadvantaged in many respects and had not been able to share, on the same terms as other members of the community, the growth of national prosperity. The new legislation proposes to give people with severe disabilities legal rights to extra services and supports to be able to live a normal life together with other people in society. The services covered by this new legislation are: counseling; other kinds of professional support; personal assistance; short stays away from home mainly as respite to relieve relatives otherwise responsible for care; daily activities (but not work) in day centers or other kinds of occupations; specially designed housing, leisure, recreation; and so on.

A number of people have used the law to demand as their right the support and services they require from public authorities. They have used the system of appeal, which is seen as a very important instrument for individuals to confront the power of public authorities.

The use of judicial review has also been successful. The courts are protecting the legal rights to services for persons with disabilities. However, the rule of law does not seem to hold the same importance for some public authorities where a number of county councils

have refused to execute court decisions. The role of legislation is ambiguous as a means of creating welfare, equality, and self-determination for people with severe disabilities. Laws seem to cover up underlying disagreements as to what specific goals ought to be pursued. The interpretation of the law makes it obvious for many people who are disabled that the right to services is not always a question of self-determination. Often, it is a question of disability, gender, class, and power.

The main problem we face in Sweden and, I think, in most other countries in the world is that the interests of disabled people are not given priority in the development of society. We must not only question the interpretation of concepts such as "normal" and

"Normalization," but also "rights" and "rights thinking." There is no doubt that in Sweden, the use of rights legislation has increased the access of disabled persons to the social services they need and that make their lives easier. But rights legislation has not meant more influence and participation in society. Moreover, disabled persons share this experience with other groups of citizens who do not have disabilities, such as women, children, refugees, and elderly persons. At the heart of this problem, we find questions of power, gender, and social relations between citizens. Thus, what must be done to change society in order to establish social justice for all? The values and normative structures in rights legislation can provide a vehicle for such change.

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