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**DESGAITASUNA,
ESKUBIDEAK
eta INKLUSIOA**
NAZIOARTEKO
KONGRESUA



CONGRESO
INTERNACIONAL
**DISCAPACIDAD,
DERECHOS
e INCLUSIÓN**

IZENBURUA-TÍTULO:

INDEPENDENT LIVING MODEL – THE
CLOSURE OF INSTITUTIONS AND
ACCESSING RIGHTS



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1. INDEPENDENT LIVING INSTITUTE (ILI) IN SWEDEN

The Independent Living Institute (ILI) is a policy development center specializing in consumer-driven policies and promotes the self-determination of people with disabilities.

Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent Living means that people with disabilities demand the same choices and control in their every-day lives that all other non-disabled brothers and sisters, neighbors and friends take for granted.

"Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves - just as everybody else. To this end we must support and learn from each other, organize ourselves and work for political changes that lead to the legal protection of our human and civil rights. We are profoundly ordinary people sharing the same need to feel included, recognized and loved." (Adolf Ratzka, the founder of ILI)

1.1. ILI's current projects and activities

Assistanskoll provides information, facts and statistics, analysis and advice to assistance users, their families and assistants in the choice of assistance providers. Assistanskoll keeps the public informed about the rapid changes taking place in legislation, case law and market development.

Disability Rights Defenders (DRD)- know your rights, use them is a network of individuals and organizations with an interest in disability rights and disability law. The purpose of the network is to spread and deepen legal expertise about disability rights among disabled persons, disabled people's organization, lawyers and law schools. DRD invite people interested in disability rights to join the closed facebook-group "Disability Rights Defenders" and to share their experiences, methods and advice and together spread information and knowledge on how to use the law as a tool to implement and defend the rights of disabled people. DRD welcome contributions in form of brief descriptions of legal cases, court decisions, references to legislation, publications,

reports as well as announcements of events, learning and funding opportunities. The content shared in the facebook-group is summarized in a newsletter four times a year.

Disabled Refugees Welcome (DRW) is a 3-years project run by Independent Living Institute. The funding is provided by the Swedish Inheritance Fund.

The purpose of the project is to create new methods which will facilitate to better reception process and more accessible integration politics for disabled newcomers.

Article 19 as a tool is a 3-years project that contributes to strengthening the understanding of self-determination and prerequisites to participation in the community of disabled people.

“Article 19” refers to the UN Convention on the Rights of Persons with Disabilities. The project disseminates information to rights bearers, works with analyzing compliance of the degree of implementation of the rights and state obligations under article 19 of the UN Convention on the Rights of Persons with Disabilities in cooperation with rights bearers in different parts of the country, and proposes legislative changes to better implement the rights in Sweden. The funding is provided by the Swedish Inheritance Fund.

Independent Living Institute (ILI) make activities to promote the self-determination of people with disabilities, which means:

- Anti-discrimination
- De-medicalization
- De-professionalization
- Self-representation
- De-institutionalization

2. DISABILITY POLICY IN SWEDEN

Swedish government made a decision year 2017 about a new “Disability policy”. It is based on the UN Convention on the Rights of Persons with Disabilities. The policy safeguards the rights and interests that people with disabilities have in society. Several areas are covered by this policy, including labour market policy and education policy. This page is currently being updated with additional information.

The national goal of disability policy is, with the UN Convention on the Rights of Persons with Disabilities as a starting point, to achieve equality in living conditions and full participation in society for persons with disabilities. The goal is to contribute to increased gender equality and to take into account the children's rights perspective. This new target will replace the current national disability policy goals.

New focus for work in order to achieve the national goal, the implementation of disability policy should be directed towards the four areas:

- the principle of universal design,
- existing shortcomings in accessibility,
- individual support and solutions for individual independence; and
- to prevent and counter discrimination.

The starting point for disability policy is the principle of universal equality and equal rights. Central, local and regional governments are jointly responsible for ensuring that people with functional impairments enjoy good health and financial and social security and for improving individuals' chances to independence.

Swedish municipalities are responsible for the daily support of people with disabilities. Legislation and supervision of its application are important tools in improving living conditions for people with functional impairments. Care, service and education are governed by a number of laws such as the Social Services Act (SoL), the Health and Medical Services Act (HSL) and the Education Act (Skoll). Regional County Councils are responsible for healthcare.

Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) is a law setting out entitlement to a number of basic measures for people with extensive needs. LSS-law prepared the process in deinstitutionalization and pointed out important support for people with disabilities.

The State Department - Inspektion av Vård och Omsorg (IVO) - oversees the services of the disabled and also the housing services. The focus of the monitoring is especially on the disabled person's ability to speak for themselves, their participation, the right to self-determination and the ability to live an independent life.

Organizations for the disabled people have participation in Swedish disability policy and it is regarded as an important component of the democratic process in central, regional and local level. Many organizations receive government grants.

3. DEINSTITUTIONALIZATION PROCESS IN SWEDEN

The history of people with intellectual disabilities in Sweden is a sad story of inhumanity and discrimination against persons with intellectual disabilities. Living in institutions has been forgotten, planted routine and medical examinations. After the institutions have been removed, the situation is another. People with intellectual disabilities are full citizens who have statutory right to a good quality of life.

After big institutions became closed it is still important to fight against institution habits, reforms and practice that reduce opportunities for independent living.

3.1. Decisions on the removal of institutions

In the 1960s, there were still around 14,000 intellectual disabled persons in institutions and the responsibility for the necessary support measures was in the Swedish state. In 1967 Care Act (Omsorgslagen 1967) recognized the need to plan for people with intellectual disabilities living in institutions to move from institutions to open support in society. Responsibility transferred from the state to regional County Councils Administration and finally 1993 have municipalities been responsible for the support and services. This change of responsibility from the medical administration to the municipalities had a symbolic meaning. A person with intellectual disabilities is not a patient but an equal citizen of the municipality. Only special support for medical care such as specialized centers, rehabilitation measures, aids and interpretation was left to the regional medical administration.

The Law on the Disabled Care Act from 1967 was abolished in 1994 and the special legislation LSS (Act concerning Support and Service for Persons with Certain Functional Impairments) was replaced. The LSS Act regulates the rights for 1) Persons with a disability or autism. 2) Persons

with brain injury. 3) Persons with a large, permanent physical or mental disability which causes big difficulties in everyday activities and leads to the need for versatile support. More than 80 percent of people receiving LSS law support are people with intellectual disability or autism disability. The contents and rights of the LSS Act are based on the results of a large-scale disability study. The study investigated the living conditions of people with disabilities compared to other Swedes and sought to correct the shortcomings with the specific support measures / rights stipulated in the LSS Act.

LSS Act set also a time limit for the closing of institutions by the year 2000. The development of deinstitutionalization was practically not rapid enough and in 1997 there were still totally about 1000 intellectually disabled persons living in 52 institutions in Sweden.

Urgent legislation 1997 as a complement to LSS Law was needed to speed up development work. The law stipulated that the special hospitals should be removed immediately in 1997 and all people living in institutions had to move out to society by the year 2000

Municipalities were asked to explain to the Social Government how the sites of each person belonging to the municipality's responsibility will be replaced by the year 2000. There was also a need for a special permit from the Social Government to continue the operation after 1/1/2000 if the completion of group residences under the LSS law was delayed.

3.2. Quality requirements for housing

The quality standards presented by the LSS Law have been important in designing a new kind of housing. Brave decisions about the quality standards of housing have prevented building of new big institution complexes. The plants have really been transformed into society.

A person with a disability had to have a private apartment that includes cooking and bathroom facilities about 40 m² and the housing units had to be small. The LSS Act of 1994 clarified the quality requirements and set the maximum size of the group home to 5-6 apartments with own kitchen and bathroom and include even common spaces.

A group apartment must be in accordance with the LSS law in the normal living environment and not be designed closed to category buildings such as hospitals, nursing homes, health centers, etc. One important quality requirement is that several group residences may not be present in the same building or gateway.

After the deinstitutionalization, the small group housing begin to be called “new institutions” as opposed to own accommodation in society with access to personal assistance, support and service.

3.3. Fear of deinstitutionalization

Decisions to close institutions have been partly welcomed but also met with uncertainty and concern. The biggest opponents were found in staffs, relatives and on organizations of disabled people. The staff was concerned about the future: What happens to my employment? Where will my work be placed in the municipality? The family and close relatives of people with intellectual disabilities feared that support systems in society would not work reliably. They were also worried about the way in which people with intellectual disabilities will be treated in the neighborhood.

People with challenging behavior and in need of massive support were just those people who made the most successful move from large institutions to small housing units. The environment became more peaceful and increased the sense of security. The number of staff they needed to have connection with in the new housing units became much lower and had a positive effect on the daily continuity of the support.

General and also targeted information about national disability policy is an important part of a successful integration process. Knowledge about how disability and various cognitive difficulties affect different situations is needed. Neighbors' prejudices and negative attitudes towards group residences have been an important target for relevant information. Awareness rising is expected to affect prejudices and improve the attitude of the environment to a disabled person.

3.4. New working methods in residential units

The adaptation of staff and working methods has been a major challenge for many residential units in Sweden. A new challenge is how we succeed in our efforts to support people with intellectual disabilities to participate and become part of society after living in a long-term institution. Relocating to private support from collective support was one of the key issues after deinstitutionalization.

The organization and cost of small housing units have demanded careful economic planning. At the same time, it must be possible to guarantee the support of the people living in the unit and meet the high quality standards set by the LSS. Participation in leisure activities can take place either in groups or individually.

Individual support promotes the participation of a person in activities that are personally interested. Individual arrangements for each person increase self-determination.

3.5. Standard of living today – after deinstitutionalization

Studies on the standard of living of people with intellectual disabilities in Sweden show that the standard of living of people with intellectual disabilities compared to the "average Swedish" is still considerably lower when it comes to the economic situation, the level of school attendance, participation in employment, leisure time and health. The potential for computer and internet access also differs considerably from that of other citizens. The only exception is the quality of housing including TV and telephone connection. The Swedish standard of living for people with developing disabilities regarding housing conditions is comparable to that of other Swedes.

4. THE SWEDISH PERSONAL ASSISTANCE ACT

The Personal Assistance Act has been in place since 1994 as an important part of reforms in time of deinstitutionalization. Government commissions and researchers point to unquestionable and significant improvements in the recipients' quality of life in comparison to what they had before.

Before 1994 services were in the form of municipal community-based services or people with disabilities lived in semi-institutional cluster housing facilities.

Swedish national personal assistance policy was highly influenced by a pilot project with personal assistance initiated and run in Stockholm in 1987-1989 by the Swedish branch of the international Independent Living Movement. Therefore, its features are influenced by the Independent Living philosophy.

Personal assistance for eligible persons is a legal entitlement and independent of the budget of the funding agency, the tax-funded National Social Insurance (Försäkringskassan). Needs are expressed in number of hours per week. Finances follows the user, not the service provider. Costs are covered such as market wages, social insurance fees, administration including a budget for accompanying personal assistants' costs for transportation, meals and accommodations.

Currently 16,000 Swedes receive cash benefits for Personal Assistance (Sweden's total population is near 10 million). Nearly one thousand private and public entities offer Personal Assistance services. The Swedish Personal Assistance Act can serve as an example of a policy for demand-driven services, because it creates a personal assistance market by enabling recipients to buy services or employ their own assistants directly. Assistance needs in terms of the number assistance hours needed by the individual are assessed by case managers at the tax-funded Social Insurance Fund. Each month recipients get an amount that corresponds to the costs of these hours. Users pay white wages at going market rates for this type of work. Private companies can cover their expenses and make even modest profits.

The 16,000 recipients of the direct payments for personal assistance together employ some 50,000 personal assistants on a full-time basis. Personal assistants – often immigrants, young people in transition between school and working life, free lancers and part-time workers.

5. CHALLENGES OF TODAY

Regular investigations and suggestions on how to increase the costs of support and service to people with disabilities can be prevented. Many of the proposals and even implemented changes have meant that access to support has deteriorated.

Regarding personal assistance it has been discussions and investigations about what is considered to be basic needs in every day life. Several children and adults with disabilities have received reduced assistance and lost the opportunity to live as others. The risk of moving from one's own home to collective housing solutions is increasing.

Persons who acquire a disability after the age of 65, by law, cannot get personal assistance by stately payments and have to rely instead on residential institutions or local governments' community based services.

Lack of knowledge of history regarding disability issues make risks that prevent group housing are developing bigger and into more and more institution-like.

Decision-makers, staff, community actors and the public need knowledge about the UN Convention on the Rights of Persons with Disabilities.

The struggle for access to the necessary support efforts and access to the community of society is ongoing.