

Freedom to Choose with Whom, Where, and How You Want to Live

– Deinstitutionalisation (DI) in Sweden



Supported by:

 Independent
Living Institute
independentliving.org

 Bidragstiftelsen

STIL
Personlig assistans och politisk påverkan

Stockholm 2022

Riitta-Leena Karlsson – BA Social work

Jamie Bolling – MA Social anthropology

Editing: Emma Åstrand

Illustrations: Mari Siilsalu

Layout: Lernberger Reklam, www.lernberger.com

Print: Excellent Print & Design, Stockholm, 2023

Content

STIL's Second Edition Foreword	5
Bengt Westerberg's Foreword	8
Introduction	10
Definitions and Basic Principles	12
Background	19
The Institutional Era in Sweden	22
Influence of Disability Rights Organisations	30
Reforms Before Deinstitutionalisation	34
Laws Concerning Deinstitutionalisation	37
Closing of Institutions	40
Support and Service to Disabled Persons	43
What was the Result? The Aftermath of Deinstitutionalization?	52
Swedish Disability Policy	61
Conclusions for the Future – What Have We Learned?	63
Concluding Reflections and Recommendations	66
Final Remarks with a Summary of the Recommendations	71
Appendixes	73
Footnotes	90

STIL's Second Edition Foreword

In this report, Riita-Leena Karlsson and Jamie Bolling describe how Sweden has taken steps to abolish institutions, in addition to other measures needed to meet the demands described in the UN Convention on Rights of Persons with Disabilities. For STIL (The Founders of Independent Living in Sweden), as well as other people and organisations working for de-institutionalisation and everyone's right to live a self-determined life in the community, this report is an important memento.

Swedish history is full of dark testimonies of institutionalisation and abuse of persons with disabilities. Testimonies that were kept silent, and hence are not known for the public. Instead, Sweden and its welfare state has a reputation of being exceptionally good. But the Swedish welfare state was, and still is, not for everyone. People with disabilities, including small children, were throughout the 20th century often institutionalised for all of their lives. Families were told to forget and go on with their lives. Life in institutions was usually hard, sometimes like a living nightmare. The most infamous example is the toffee experiment at Vipeholm in the 40s and 50s. An experiment carried out with no consent from neither the patients nor their families, with much suffering and sometimes also death for those exposed.

Fortunately, institutions such as Vipeholm now belong to the past, but even for those outside these facilities life continued in an institutionalised manner. There are many stories of the trauma of being nothing but an object of benevolence. Someone had more than 60 unknown people in their home in one month. Another had to make do with potatoes, onions, and carrots, since that was all they knew would always be available at the local market when the home care service did their weekly shopping. Special transportation service had to be booked days ahead, and there were rules regulating the amount of times the same staff could attend an individual. Supposedly the risk of growing too close would otherwise be too big. All of this happened as late as in the 1980s.

Persons with disabilities had to become experts in how to manipulate and find strategies to gain even a smidge of control in their daily lives. Of course, this way of living creates traumas for all those involved. Deep wounds that never heals. Those who have been forced to live like this never want to go back, and there are those stating they would rather commit suicide than being institutionalised. When the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) was enacted in 1994 there were many hoping, and believing, that the days of institutions had finally reached their end.

And LSS was in many ways a reform for freedom. Personal assistance made it possible for us, persons with disabilities, to educate ourselves, work, start a family, have and participate in hobbies, and to choose for ourselves where to live. But, good intentions notwithstanding, Sweden still has a good way to go before all institutions are gone. According to the

definition of the general comment No. 5 in the UN Convention on Rights of Persons with Disabilities, the characteristics of an institution are, among other things:

- The necessity to share assistants with others.
- Lack of, or limited, influence over who will assist you.
- Lack of control of everyday decisions.
- Lack of possibility to choose who you want to live with.
- Inflexible routines, not considering personal choices and personal preferences.
- Paternalistic views on what services to offer and how.

Looking at the criteria above, it is easy to see that most group homes can be regarded as institutions. The same goes for services like home care, foster homes, and to some extent, accompanying services. Even if it may not be entirely obvious, a decision on personal assistance can also lead to an institutionalisation. For example, it might be the case when a provider of personal assistance allows an employee to work for several individuals on a schedule that fits the employee rather than those utilising the service. Or if the provider or the personal assistants decides what to be done and when. The institutionalised and paternalistic approach is evidently deeply rooted in the Swedish welfare image, allowing that kind of behaviour, regardless of the fact that the right to personal assistance has been granted since the 1990s.

But not only are there still institutions up and running, they are increasing in numbers. During the last decade, the rights of people of disabilities have diminished; assistive aids and technology, special transportation service, car allowance, accompanying services, not to mention personal assistance. But of course it is not as if our needs are waning just because the finances are being cut. People, who previously lived independent lives, able to partake in society due to their personal assistance, are today forced to make do with institutional solutions. The number of people with disabilities, dependant on limited home services instead of personal assistance, are increasing. Municipalities are continuously building new group home facilities. Even orphanages are under construction. And this just because parents succumb when they receive no support.

This is a most disturbing development, with no regard to Sweden's commitments to the UN. Financial cuts and revoked decisions are usually based on economic reasons, an argument that is not valid. Seen from a socio-economic perspective, it is more about where the money comes from. Group homes and home care are not cheaper, rather the opposite. Worn out family members and other relations create other costs – as do unemployed personal assistants. Also, the additional costs of all the trauma the cuts bring to persons with disabilities should also be taken into consideration. Not only

is it expensive – it is also unnecessary and unworthy. And even if there are still those who are granted the support and service they need, the worry and stress of risking losing it all create other issues.

For those involved it is hard to grasp how this backlash can be happening when we do not have to look far back in order to find horrific examples of how bad it has been. But, in this report we are shown how change is still possible. This is the very reason for its existence. And this is why you must read it.

Jessica Smaaland

Political Secretary, STIL

***But not only are ”
there still institutions
up and running, they
are increasing in numbers.***

Bengt Westerberg's Foreword

In this publication, Jamie Bolling and Riitta-Leena Karlsson examine what is required to provide persons with disabilities with opportunities to live like others. The UN Convention on the Rights of Persons with Disabilities (CRPD) and existing Swedish laws, especially the Social Services Act (SoL) and the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS), support this goal. However, as the authors note, the implementation recently has become restrained in a manner that has impaired the possibilities for many people to do just that.

The motivation of the cuts in services is, of course, the costs, and particularly the costs of personal assistance. According to a recently published book, the costs of the national assistance allowance are higher than the costs of all the authorities under the Ministry of Justice, such as the police, the legal system, and the correctional system. Something which is deeply criticised. Many people seem to think it is too costly to give persons with comprehensive impairments the opportunity to live like others. But, of course, it is not said in quite such an explicit way. Instead, it is said that these persons should be allowed to live a life like others, but it must be achieved with cheaper support services than personal assistance. What those might entail although remains unsaid.

The problem is that many persons with comprehensive impairments need the assistance of others to manage what other people can do unaided. It can come down to such “simple” tasks as getting dressed and undressed, managing your personal hygiene, going to the toilet, eating, communicating with others, and moving about. Most of us do all these things effortlessly. But for many people with severe impairments, it is not so simple. Also, even if they would rather manage all this by themselves, it is just not possible. In many cases, they need assistance from others. There are 8,760 hours in a year. This means that six persons working full-time are needed to provide this assistance for someone who needs assistance around the clock. Recipients of the national assistance allowance presently receive an average of 130 hours per week, or 6,760 hours per year. This is the equivalent of approximately 4,5 full-time positions. If the persons filling these are to be paid, it will of course cost money.

What then is the alternative to personal assistance? We have some knowledge of the consequences for those who lost their right to the national assistance allowance. In 2017, I looked into this. In many cases, personal assistance has been replaced by – that’s right! – personal assistance. The municipalities simply have found that there was no other alternative. So they have granted municipal personal assistance but, often, with fewer hours (about 75 percent of the original amount). In other cases, persons with disabilities have been forced to move to a group home or have had their personal assistance replaced with home care services (often with a severe cut of hours; sometimes 130 hours of assistance can be turned into 30 hours of home care service). It is evident that these alternatives involve a massive decrease in the

living standard for the concerned and reduced opportunities to live as others. How much could we save if the assistance allowance was completely replaced by such alternative support services? The costs of the alternatives would for the State and municipalities amount to 80–90 percent of the costs of the assistance allowance, meaning the costs would only decrease 10–20 percent despite the massive reduce of living standards for the concerned persons and their next of kin.

For those with comprehensive impairments, personal assistance is often the best solution. But for many, different types of housing with services can work well, especially if the group consists of individuals who like each other, if there is enough staff to enable different activities outside the home, and if they can get help from an attendant or contact person to go out for individual activities and not be limited to group activities. However, as is emphasised in this publication, this is often not the case. For example the availability of attendant services or contact persons that make it possible for the residents to go out on individual activities are often non-existent.

There are strong reasons for Sweden to grant more individuals personal assistance if we are to fulfil the goals of the UN convention as well as our national laws. If we were to go back to the assessment criteria applied as recently as approximately 2015, an additional 3,000–4,000 individuals would probably have assistance today. Furthermore, the service in housing with special services would need to be improved so that more residents can go out on individual activities. In addition, the possibility of using attendant service for, among others, persons with visual impairments need to be improved. It does not feel like an extravagant cost to enable a few thousand persons with comprehensive impairments the opportunity to live like others. As these lines are written, Lena Hallengren, the minister of social affairs, announces that after several years of cuts, the government will propose a strengthening of the right to personal assistance. Hopefully, this will be the first step for Sweden to become a role model for disability rights once more.

And let this publication be yet another step in that direction!

Bengt Westerberg

Minister of Social Affairs 1991–1994, when the LSS including personal assistance was enacted.

For example the availability of attendant services or contact persons that make it possible for the residents to go out on individual activities are often non-existent. ”

Introduction

It has only been 20 years since we in Sweden realised that life in institutions involves a violation of human rights, and since the large institutions were closed.¹ How can it be that Sweden once again finds itself in a situation where there is a risk of increasing institutional placements? Why is the development going backwards when concerning the living situation of disabled persons? Why is this happening when the UN Convention on the Rights of Persons with Disabilities (CRPD) – which purpose is to improve the living conditions of disabled persons – should be implemented?² Why?

The present-day view of a life considered worth living is modelled on historical ideals. Without knowledge of this prehistory, seemingly innocent views can, after a time, make society diverge onto a path leading away from the idea of all humans' equal worth.³ Therefore, it is important to recall the undignified living conditions of the institutional era, and describe decisions and processes that resulted in the closure of the old institutions.

In other countries, the Independent Living movement struggles to close institutions, and in many countries, Sweden is used as a role model for deinstitutionalisation. The European Network on Independent Living (ENIL) and its member organisations have done study visits to Sweden to learn about the experiences of deinstitutionalisation. A film was produced by ENIL with the title “Institutions are NOT Solutions: Learning from the Swedish Experience” to disseminate knowledge of the subject.⁴ But will Sweden remain a role model in the future?

This publication is produced by the Independent Living Institute (ILI) in Sweden and describes miserable parts of the history of Sweden when disabled persons lived in large institutions, hidden and forgotten outside of their families and the society. How was the process connected with decisions and implementation of deinstitutionalisation (DI)?

The publication begins with a section on important definitions and basic principles, as well as background information on the situation of the present day. The section on the institutional era first describes the situation for

1 SFS 1997:724. Lagen om avveckling av specialsjukhus och vårdhem.

2 General Assembly 2006: 61/106. Convention on the Rights of Persons with Disabilities. https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A_RES_61_106.pdf (Retrieved 2023-01-09).

3 Persson, Margareta. Gamla synsätt spökar än – funktionshinder genom tiderna. Stockholm: Instant Book. 2018. 13

4 ENIL. Institutions are NOT Solutions: Learning from the Swedish Experience. YouTube. 2016. https://www.youtube.com/watch?v=aFxBZ2iXc4&ab_channel=EuropeanNetworkonIndependentLiving-ENIL (Retrieved 2023-01-03).

children and adults in institutions and, after that, the process of closing the institutions. Tabled summaries of decisions and events during this era are presented in two appendixes to the main text.⁵ The most important laws on the deinstitutionalisation process and today's laws regulating support and service outside the institutions are presented. The goals of Sweden's current disability policy are presented in a section of their own.

The publication also illustrates the work of the Independent Living movement on and development of personal assistance, which has resulted in more disabled persons being able to continue living in or moving out of institutions into their own homes. The development of personal assistance and other social services was of big importance for the design of the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS). The LSS-reform facilitated the closure of large institutions, regulated support services in daily life, and improved living conditions for many persons with comprehensive support needs.⁶

The importance of the UN Convention on the Rights of Persons with Disabilities (CRPD) is emphasised in this publication.⁷ According to the convention and its general comment number 5 to article 19, nobody shall live in institutions.⁸ In the section on CRPD and article 19, the importance of the right to self-determination is described. Recent challenges to the right to self-determination and participation in the community are highlighted.⁹ The main theme of the publication is deinstitutionalisation, and, therefore, it focuses on the right to live where and with whom you want, as well as having access to necessary support services. The challenges of today, with risks of institutional working methods and re-institutionalisation, are made visible. Finally, reflections and recommendations for the future are put forth.

5 Bilagor: Table 1 – Institutioner och skolgång, Table 2 – Institutionsepok och dess avveckling.

6 SFS 1993:387. Lag om stöd och service till vissa funktionshindrade.

7 General Assembly 2006: 61/106. Convention on the Rights of Persons with Disabilities. https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A_RES_61_106.pdf (Retrieved 2023-01-09).

8 United Nations. General comment No.5 on Article 19 – the right to live independently and be included in the community. United Nations. 2017. <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live> (Retrieved 2023-01-03).

9 General Assembly 2006: 61/106. Convention on the Rights of Persons with Disabilities. https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A_RES_61_106.pdf (Retrieved 2023-01-09).

Definitions and Basic Principles



What is the understanding of different concepts within CRPD and Independent Living? Which concepts are important today? What does it mean to live in and be a part of the community and have a self-determined life? The concept of an institution means different things in different contexts. This section contains definitions that are important for the process of deinstitutionalisation, as well as descriptions of some recent concepts and basic principles.

Institutions

The general comment number 5 to article 19 of CRPD contains the definition of institu-

tions.¹⁰ Institutions are not just a specific type of building, but are defined by whether the individual is denied the freedom of choice and control. Even smaller group homes with individual flats can be regarded as institutions if the residents lack freedom and self-determination; if, for example, they have not chosen to live there, or if they, against their will, share staff or lack control over their daily lives. Even a family can function in an institutional manner if the concerned individuals lack the possibility of self-determination. According to CRPD, it is important that everyone shares the same definition of what constitutes an institution so that community support can develop in the right direction and institutions are closed.

¹⁰ United Nations. General comment No.5 on Article 19 – the right to live independently and be included in the community. United Nations. 2017. <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live> (Retrieved 2023-01-03).

Whether one can live a self-determined life and be included in the community is dependent on the environment outside the institutions. So, it is not “only” about living in a specific building or institutional environment but, first and foremost, about which personal choices the individual has at their disposal and what autonomy they have. Smaller group homes with four to six residents can be just as far from a self-determined life as large scale institutions. The same applies to single dwellings if they have characteristics defining large institutions; what the Independent Living movement calls mobile institutions.¹¹

Even if institutions can vary in size, name and organisation, they often share some common characteristics. This can, for example, be by being forced to share staff/assistants with others and totally lacking or only have a limited influence over who it is that will assist you. It can be by being isolated from a self-determined life included in the community, lacking control over daily life decisions, or that you cannot choose whom you live with. It can be inflexible routines that do not consider the individual’s will and preferences. It can involve the individual’s participation being limited to group activities. It can involve the individual being subjected to a paternalistic approach when receiving services and monitored in the housing situation.

In institutions, an unproportionally large number of disabled residents are often living together. Such environments can, of course, offer the residents a measure of choice and control, but the choices are often limited to specific areas of life and are not chang-

ing the fact that institutions, as a rule, act segregating.

Deinstitutionalisation requires structural reforms that guarantee necessary support and individual dwellings and support for children/youth within their families. “Family like” institutions are still institutions and cannot replace the care of a family. It is occasionally claimed that certain disabled children and youth need so much help that they cannot remain living with their families. Then, the proposal can be that they must live in children’s group homes where parents and siblings occasionally can visit them. Placing children in specific group homes should only be an issue when the parents lack care and parental abilities. Children/youth with comprehensive needs have the right to the support services needed to remain, live and grow up in their families and experience friendship with other children in preschool, school, and leisure time. When life in the family is not possible, living with a foster family should be prioritised over a group home.

The Swedish Agency for Participation (MFD)¹² translate living independently with the term “självständigt liv” (which is more related to the English concept of “not dependent on others”) in the Swedish version of the general comment number 5 to article 19 of the CRPD. Within the Independent Living movement, we use the concept of *self-determined life/self-determination*, which means that disabled persons are provided with all necessary support services to have access to choice and control over all decisions in their lives. Individual autonomy and self-de-

11 Ratzka, Adolf. Personlig Assistans: Ett försök till en operationell definition. Independent Living Institute. 1992. <https://www.independentliving.org/toolsforpower/tools15b.html> (Retrieved 2023-01-03).

12 Myndigheten för delaktighet. Konventionen om rättigheter för personer med funktionsnedsättning Allmän kommentar nr 5 om ett självständigt liv och att vara inkluderad i samhällsgemenskapen. Stockholm: MFD, 2020. <https://www.mfd.se/contentassets/10cbb4a4f8e34299beb96d965c77e8fb/2020-2-allman-kommentar-5-sjalvstandigt-liv-inkluderad-i-samhallsgemenskapen.pdf> (Retrieved 2023-01-03).

termination are fundamental to a self-determined life. It includes having access to transport, information, communication, housing, work with decent employment conditions, personal relations, clothes, food, hygiene, health and medical services, religious and cultural activities, etcetera, sexual and reproductive rights, as well as personal assistance when needed. The development of individual identity and personality is dependent on access to these things. Where we live and with whom, what we eat, if we want to take a lie-in or go to bed late at night, be indoors or outdoors, use a table cloth and lighted candles, have a pet or listen to music. These are all activities and decisions that make us into the unique individuals we are. A self-determined life is an indispensable part of an individual's autonomy and freedom but does not necessarily mean that you live alone.

A self-determined life is also not the same as the ability to carry out daily activities unaided. Instead, a self-determined life involves the right to choice and control over the actions and decisions that make us into the unique individuals we are in line with the respect for the individual's dignity and personal autonomy that is inscribed in article 3a of the CRPD. That, according to the Independent Living movement, is, self-determination and all disabled persons must not be deprived of the opportunity to choose and have control over their lifestyle and daily life activities.

Being included in the community is defined in the general comment number 5 to article 19 of the CRPD and is connected to the principle of full and efficient participation and inclusion in the society. The right

to be included in the community involves, among other things, the right to live a full social life and have availability and access to all the services provided to the public and the individual support services that make it possible for disabled persons to be fully included and participating in all parts of society. A life included in the community (community living¹³) is simply to, on equal terms as others in the community, have access to choice, control and freedom, as well as individually adapted support, and availability and access to all support services and activities within the society. For example, it can include access and availability to the political and cultural sphere, public meetings, sports events, cultural and religious festivals, and other activities where a disabled person wants to participate. It can also involve access and availability to public services such as housing, transport, shopping, education, occupation, leisure activities, and other things, including social media.

Current terminology and our view on human beings

The discourse of the institutional era exudes that period's view of disabled persons with an undignified vocabulary where disabled persons are called, among other things, idiots, imbeciles, retarded, invalid, low-grade, cripples, and ineducable.¹⁴ Persons with physical impairments could be called CP, hunchbacks, or clubfoot.¹⁵

Today, many different terms are present within Swedish disability policy. The term "*handicap*" is not used as an official term in Sweden. "Handicap" meant the loss or

13 ENIL. FACT SHEET: Independent Living. 2013. <https://enil.eu/independent-living/> (Retrieved 2023-01-18).

14 Grünewald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 15.

15 DHR. *Levande röster i vår historia*. Förlag Brevskolan. 1984. 39.



limitations of the ability to participate in the community on equal terms.¹⁶ Nowadays, the term impairment, which means impaired physical, mental, or cognitive ability, is used. Functional variation means that all human beings have their own set of abilities, strengths and weaknesses. Functional variation is sometimes used as a synonym for persons with disabilities, which creates confusion about who, for example, is protected under the CRPD and who belongs to a privileged public. To clarify: individuals with non-normative functional variations can be

used synonymously to persons with disabilities, while individuals with normative functional variations have a set of functional abilities that fits the normative society.

Since the UN Standard Rules¹⁷, from the beginning of the 1990s, started to use the term *disability* when the environment and deficits within society limit persons with impairments and cause obstacles¹⁸. The term disability refers to the relation between the surrounding environment and the individual. A disability is created when a person with impairment cannot participate in the com-

16 Sandén, Staffan och Tideman, Magnus. Detta är inte en politisk fråga. Högskolan i Halmstad: Wigforssinstitutet. 1997. 19.

17 Independent Living Institute. Standardregler för att tillförsäkra människor med funktionsnedsättning delaktighet och jämlikhet. Independent Living Institute. 1995. <https://www.independentliving.org/standardrules/STILStandardRegler1.html> (Retrieved 2022-12-28).

18 Socialstyrelsen. Socialstyrelsens termbank. Socialstyrelsen. 2022. <https://termbank.socialstyrelsen.se/> (Retrieved 2022-12-28).

munity because there are obstacles in the surrounding environment.¹⁹ “The relative model of disability” has both background and a strong position within the Nordic countries, where the relative model concept was discussed already in the preparations for the International Year of Disabled Persons (in Swedish “internationella handikappåret”), 1981.²⁰ Nowadays, the terms impairments and disability are used in Swedish law and public documents. The terms are also defined in the National Board of Health and Welfare’s term database. The CRPD uses the term “persons with disabilities”, which in the Swedish versions is translated to “personer med funktionsnedsättningar” (persons with impairments). The model of disability that characterises the CRPD can be viewed as a mix of the “social model of disability”, that places the cause of obstacles to participation solely in the society, and the Independent Living movement’s principles, where foremost article 19 of the CRPD is strongly influenced by the movement’s principles.²¹ Mike Oliver described and gave the name to “the social model” in 1990, which came from the British disability rights movement’s struggle for equality and the right to live included in the community from the 1970s and forward.²²

To categorise individuals by using the term impairment undoubtedly means to denote them as “deficient” in some form. Irrespective of how the environment is emphasised as causing disability, focus often remains on what is conceived as a deficit in the individual. From a realisation that an almost endless number of functional variations exist, it is possible to shift focus from the so called impairments of the individual, to the normative society that is organised in a manner that includes persons with abilities which are part of the norm and excludes other with *non-normative abilities*. To use the term “non-normative abilities” involves emphasising and critically analysing the norm that decides whom society is organised for. The term non-normative abilities appear, for example, in publications published within the project Disabled Refugees Welcome (DRW)²³, funded by the Independent Living Institute (ILI).

The Swedish term “*funktionsrätt*” (“disability rights”) is based on the right of disabled persons to be included in the community with equal opportunities. It involves the individual as a bearer of rights, and when Sweden signed the CRPD, the state committed to pursuing politics which shall provide access to these rights. The CRPD is based on

19 Beckett, Angharad E. och Lawson, Anna. The Social and Human Rights Models of Disability: Towards a Complementarity Thesis. *The International Journal of Human Rights*. Vol. 25, nr.2, 2020: 348–379.

20 Söder, M. Handikappbegreppet: en analys utifrån WHO:s terminologi och svensk debatt, Beredningsgruppen för internationella handikappåret 1981. Stockholm: Socialdepartementet, 1981.

21 Berg, Susanne och Linder, Ola. Rätten till ett självbestämt liv i samhällsgemenskapen: en essä om grunderna i Funktionsrättskonventionens artikel 19 och Independent Livingideologin. Artikel 19 som verktyg. 2019. <https://lagensomverktyg.se/2019/essa-artikel-19-och-ideologin/> (Retrieved 2022-12-28).

22 Oliver, M. The Individual and Social Models of Disability. Leeds: Centre for Disability Studies, Leeds University, 1990. <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Oliver-in-soc-dis.pdf> (Retrieved 2023-01-13).

23 Romero, S. et.al. Vågar mot ömsesidig integration. Stockholm: Disabled Refugees Welcome, Independent living Institute, 2019. <https://disabledrefugeeswelcome.se/2019/07/handbok/> (Retrieved 2023-01-03).

a human rights model of disability. In Sweden, the convention is also called “Funktionsrättskonventionen”.²⁴ The abbreviation CRPD is primarily used in this publication.

Full participation means full participation. Disabled persons must be able to live a life based on equal living conditions, freedom, and self-determination in a diverse community. Inclusion involves a process of reforms and changes so that obstacles are eliminated. Not until then, full participation based on equal opportunities with others will be possible. It can, for example, deal with school, employment, and leisure.

Intersectionality, meaning varying social identities connected to, for example, gender, skin colour, sexual orientation, and/or ability, shows of different challenges in society. With an intersectional approach, it is possible to find that varying combinations of these identities can lead to further challenges. A black woman can be facing other

challenges than black men or white women. The same can apply to a disabled person who also is female, black and/or homosexual. With an intersectional perspective, the relation between power and inequality, and categories of social identities, such as age, class, abilities, race/ethnicity, gender, and sexual orientation, can be illuminated and analysed of how these categories interact.

Empowerment is an essential concept and tool in Independent Living. It deals with the right to self-determination, individual choice, and gaining control over the elements that influence one’s life. Empowerment involves having access to the necessary resources to have power over your life and the right to use these resources according to your preferences. The concept has three ingredients: strength, power, and force. Empowerment developed as a concept in the USA in the 1920s when people wanted to claim and enforce their human rights.²⁵

Empowerment is an essential concept and tool in Independent Living. ”

²⁴ Beckett, Angharad E. och Lawson, Anna. The Social and Human Rights Models of Disability: Towards a Complementarity Thesis. The International Journal of Human Rights. Vol. 25, nr.2, 2020: 348–379.

²⁵ Askheim, Ole Petter och Starrin, Bengt. ”Empowerment – ett modeord?”. I Empowerment i Teori och Praktik, Askheim Ole Petter och Starrin Bengt, 9–12. Stockholm: Gleerups Utbildning AB, 2007.

Fundamental Principles of Independent Living

Important principles for a self-determined and equal life were set down through the European Network of Independent Living (ENIL) and the Strasbourg Resolution. They can be found in appendixes four and five to this text.²⁶

Adolf Ratzka is one of the founders of ENIL, as well as both The Founders of Independent Living in Sweden (STIL) and ILI. He has described the fundamental principles of Independent Living, which can be found on ILI's webpage.²⁷:



Foto: Helena Berzelius

“Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities, and self-respect.

Independent Living does not mean that we want to do everything by ourselves and do not need anybody, or that we want to live in isolation.

Independent Living means that we demand the same choices and control in our everyday lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work with jobs that are in line with our education and interests, and start families of our own.

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, organise ourselves, and work for political changes that lead to the legal protection of our human and civil rights.

As long as we regard our disabilities as tragedies, we will be pitied.

As long as we feel ashamed of who we are, our lives will be regarded as useless.

As long as we remain silent, we will be told by others what to do.”²⁸

Appendix number three to this text contains a longer description of the Independent Living movement and ILI.

²⁶ ENIL. The Strasbourg Resolutions. Strasbourg: ENIL, 1989, <https://www.independentliving.org/docs2/enilstrasbourgresolutions.html> (Retrieved 2023-01-04). The text is also in appendix 5 of this publication.

²⁷ Independent Living Institute. Landing page. Independent Living Institute. 2022. www.independentliving.org (Retrieved 2023-01-10).

²⁸ Ratzka, Adolf. Vad är Independent Living – en personlig definition. Independent Living Institute. 2003. <https://www.independentliving.org/defsv.html> (Retrieved 2022-12-28).

Background



There are many disabled persons who are living with the threat of cutbacks in essential social support services in Sweden today.

Many support services, which are not crucial for survival, but absolutely necessary to prevent institutionalisation, are also threatened. Reductions in the individual, and individually led, support services are the main threat to the development of a society free

from institutions. Personal assistance and other support services are being reduced or fully suspended in the society today.²⁹ Concerned families are forced to take an unreasonably large responsibility.³⁰ Many individuals fear being forced to move into special and communal housing, since they are totally dependent on assistance to manage their daily lives.³¹ Many lack family members who are able to, or can cope with, the necessary supporting role.

29 Berg, Susanne och Bylund, Christine. *Innan levde jag, nu existerar jag*. Stockholm: STIL, 2018. https://www.stil.se/sites/default/files/innan_levde_jag_upplaga_2.pdf (Retrieved 2023-01-03). 4–5.

30 Berg, Susanne och Bylund, Christine. *Innan levde jag, nu existerar jag*. Stockholm: STIL, 2018. https://www.stil.se/sites/default/files/innan_levde_jag_upplaga_2.pdf (Retrieved 2023-01-03). 34–39.

31 Berg, Susanne och Bylund, Christine. *Innan levde jag, nu existerar jag*. Stockholm: STIL, 2018. https://www.stil.se/sites/default/files/innan_levde_jag_upplaga_2.pdf (Retrieved 2023-01-03). 38.

“How will I manage if my assistance is cut?”
 “What do I do if I do not have enough hours of personal assistance?”
 “My partner is sick and cannot help me as much. Will I be able to remain living at home?”
 “How do I cope if the assistance to my child with comprehensive needs is cut?”

The quotes above are all from individuals and families who live with the support of personal assistance. The lack of assistance and other necessary support services means that, for example, children and youth risk losing the right to grow up in their families. The assistance is needed so that certain disabled persons are able to live a life included in the community, with equal opportunities as others. Disabled adults can study, work, pay taxes, start a family, be active in citizens’ associations, etcetera through the right to personal assistance, accompanying services, and other support.

Prejudice court judgments and administrative authorities’ legal interpretations have caused cutbacks in support, foremost by the Swedish Social Insurance Administration.³² The number of individuals who have the right to accompany services and contact persons is noticeably fewer. Parents of disabled children and youth have difficulty managing their everyday life. At the same time, they

are experiencing a development where the personal assistance gets reduced, and they worry about the threat of losing the right to a crucial support service.

The existence of special homes for children, called housing with special services for children or youth, within LSS, has decreased by 36 percent since 2010. However, many municipalities believe there is an increased future need for children’s service homes, since disabled children and youth with comprehensive needs cannot get satisfactory support at home when the national assistance allowance is being cut.³³ This will mean that children’s right to grow up in their families is not satisfied.

Reductions in the right to personal assistance and insufficient daily support services risk increasing reinstitutionalisation. When necessary support services are lacking, individuals who moved into their own homes when the large institutions closed twenty years ago, risk being forced to move back into institutional group homes, and younger individuals, who have never lived in an institution, risk being forced to move into one.

Elderly care and care for disabled persons are the activities where the number of abuse claims in 2020, according to the so called Lex Sarah, are the peak of all claims made. Children and adults living in special housing according to LSS are especially vulnerable groups since they often, due to different im-

32 Artikel på Assistanskoll skriven av Kenneth Westberg, TEMA – Domar i Förvaltningsdomstolarna.

33 Socialstyrelsen. Insatser för personer med funktionsnedsättning Lägesrapport 2021. Stockholm: Socialstyrelsen, 2021. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7327.pdf> (Retrieved 2023-01-03).

pairments, are not able to make their voices heard. The Health and Social Care Inspectorate (IVO) has, for several years, noted that residents in LSS-housing, among others, are subjected to acts of coercion and restraints despite this being forbidden by law.³⁴ Physical violence, abuse and psychological violations from staff also occur.³⁵ Support and service of good quality require competent staff. Unacceptable working methods and institutional habits must be eliminated.

IVO has, during the last year, opened more inspection cases concerning acts of coercion and restraints at various homes compared to earlier years. IVO has also made more intervention decisions by banning activities, injunctioning against penalty payment, and revoking licenses.³⁶

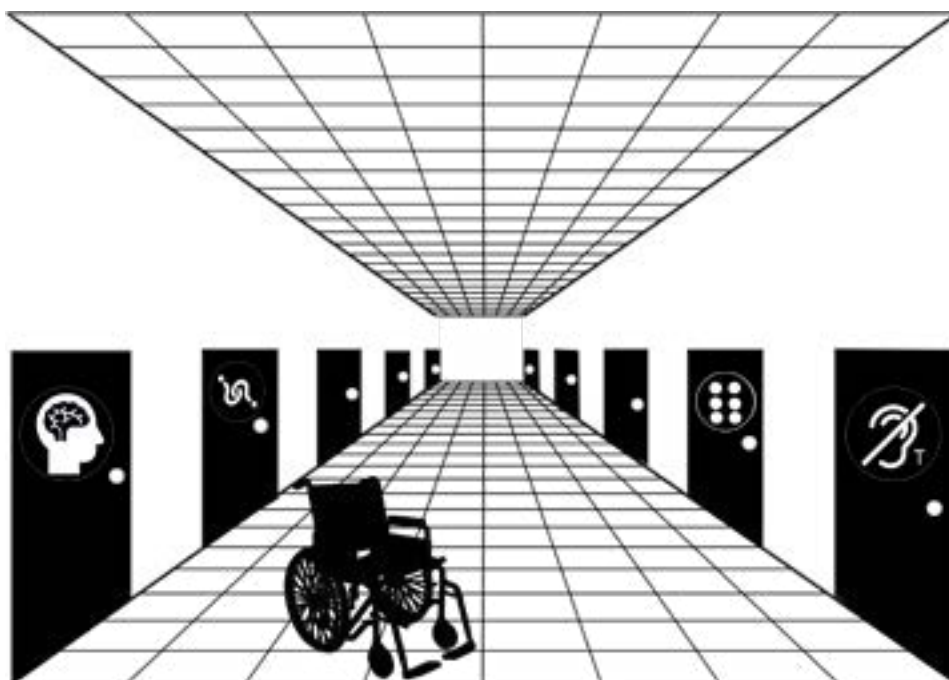
Disabled persons have always existed and will always exist. Society has used varying

ways to organise support services depending on the prevalent view on the societal versus individual responsibility. The situation is, of course, influenced by whether or not the concerned person has a family. Cutbacks in support services increase the risk of reinstitutionalisation. The general comment number 5 to article 19 in the CRPD clarifies that segregated housing, where a disproportionately large number of disabled persons must share a joint environment, should not be permitted.³⁷ A disproportionately large number of disabled persons in one housing creates segregation. Cutbacks in support services must be stopped, and disabled persons must be able to choose to have their own homes and receive the support they need. No one shall be forced to live in an institution.

How will I manage if my assistance is cut? ”

-
- 34 Inspektionen för vård och omsorg. Uppföljning av LSS-boenden Slutredovisning av regeringsuppdrag. Stockholm: IVO, 2021. <https://www.ivo.se/globalassets/dokument/publicerat/rapporter/rapporter-2021/slutredovisning-regeringsuppdrag-s2020-09593-uppfoljning-lss-boenden.pdf> (Retrieved 2023-01-03).
- 35 Inspektionen för vård och omsorg. Lex Maria och lex Sarah. IVO. 2022. <https://www.ivo.se/publicerat-material/statistik/lex-maria-och-lex-sarah/> (Retrieved 2023-01-03). Statistiktabeller för lex Sarah, 2020, Table 4.
- 36 Inspektionen för vård och omsorg. Uppföljning av LSS-boenden Slutredovisning av regeringsuppdrag. Stockholm: IVO, 2021. <https://www.ivo.se/globalassets/dokument/publicerat/rapporter/rapporter-2021/slutredovisning-regeringsuppdrag-s2020-09593-uppfoljning-lss-boenden.pdf> (Retrieved 2023-01-03).
- 37 Myndigheten för delaktighet. Konventionen om rättigheter för personer med funktionsnedsättning Allmän kommentar nr 5 om ett självständigt liv och att vara inkluderad i samhällsgemenskapen. Stockholm: MFD, 2020. <https://www.mfd.se/contentassets/10cbb4a4f8e34299beb96d965c77e8fb/2020-2-allman-kommentar-5-sjalvstandigt-liv-inkluderad-i-samhallsgemenskapen.pdf> (Retrieved 2023-01-03).

The Institutional Era in Sweden



The history of disabled persons' living conditions in institutions in Sweden is, according to Karl Grönwald, a story about inhumanity and social exclusion. Karl Grönwald was 1961 appointed chief inspector to the care of the so called "mentally retarded" at The National Swedish Board of Health, and in 1968 assistant director and medical councillor at the Swedish National Board of Health and Welfare (the Board of Health was integrated with this new authority).

In these positions, Grönwald and his co-workers controlled the county councils' (now regions) and the national government's services for persons with cognitive impairments, both children and adults. The daily life in institutions consisted of isolation, coercion, violence and routine, and medical experi-

ments. Especially regarding persons with cognitive impairments. The section about the institutional era in this publication partly uses the vocabulary used in the descriptions of this era's institutional care. The discourse illuminates the institutional era's undignified approach to disabled persons.³⁸

Karl Grönwald has left behind voluminous material and historical descriptions of the institutional era and the closing of the institutions. His books and articles constitute an important source for this publication. His book "Från idiot till medborgare, de utvecklingsstördas historia" (From idiot to citizen, the history of the mentally impaired) (2008) was the first book in Sweden trying to cover the whole history of the situation for children, youth, and adults with cognitive impairments, including the situation of the parents and the staff.³⁹ The Founders of

38 Grönwald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 15.

39 Grönwald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 11-12.

the Swedish National Association for People with Intellectual Disability (FUB) appreciated Grünewald: “He was an important person in the work to free persons with cognitive impairments from the institutions and allowing them to grow up in their families and live in society as others.”⁴⁰

The laws mirror society’s views on disabled persons. Under the ordinance of 1788, on the parish’s responsibility for the poor, every parish had the right to refuse paupers and servants who were not fully able to work from moving in. People were left to fend for themselves. In 1847, an ordinance providing a legal right to poor relief was enacted. In 1956, the Social Welfare Act (1956:2) substituted the existing law of the poor. In 1982, The Social Services Act (SoL) (1980:620), which places the responsibility of providing individuals with the support they need in the municipalities, was enacted. The law contains a special paragraph concerning support to disabled persons.⁴¹

According to Karl Grünewald, the life of children and adults with cognitive impairments have been surrounded by prejudice. During the beginning of the 1900s, the “non-educable” were completely dependent on family, homes for the elderly, mental hospitals, and, later, care homes. It was generally thought that these individuals ought to be “protected against the evil society”. Later this changed to the opinion that “the society should be protected against them”.⁴²

The ideology of eugenics formed the of-

ficial view of persons with “mental retardation” during the years 1910–1940. This meant, among other things, that the parliament passed laws both on obstacles to marriage in 1915 and, later, on sterilisation in 1936 (revised in 1941). The ignorance about life in institutions lasted until the 1950s, when the press started to write about abuse, and more people started to make reports on the insufficiency in the care of the people with mental impairments.⁴³

Through his travelling inspections, Karl Grünewald was one of the persons who strongly contributed to disclosing the misery and abuse. “At an inspection of Vipeholm in 1964, I noted that 100 patients actually never got out of bed. They had distorted, bony bodies, and were sullen and autistic. Cowering, they lay like wrinkled apples under the covers.”⁴⁴

Children and Youth in Institutions

When FUB was founded in the 1950s, the living conditions for children with cognitive impairments involved being hidden or forgotten. Parents were advised to dispose, forget, and get new children. The consequence for the child was a passive existence in large wards in institutions. But there were parents who hid their children at home.⁴⁵

Thousands of children with varying physical impairments have lived in institutions and attended school in institutions. For example, for almost 100 years, Eugeniahemmet in Stockholm was an institution with

40 FUB. Grünewalds insatser för personer med utvecklingsstörning. FUB. <https://www.fub.se/om-fub/historik/Grunewalds-insatser-for-personer-med-utvecklingsstorning/> (Retrieved 2022-12-28).

41 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 12.

42 Grünewald, Karl. Från idiot till medborgare. Stockholm: Gothia Förlag AB. 2009. 63–76.

43 Grünewald, Karl. Från idiot till medborgare. Stockholm: Gothia Förlag AB. 2009. 101–122.

44 Grünewald, Karl. Från idiot till medborgare. Stockholm: Gothia Förlag AB. 2009. 427–444.

45 FUB. Historik. FUB. <https://www.fub.se/om-fub/historik/> (Retrieved 2022-12-28).

schooling for children with mobility impairments. “Incurably sick children” from the whole country were to be accepted for schooling and medical care. Eugeniahemmet was a closed world with locked gates and high fences where many children spent their entire childhood. Eugeniahemmet was closed down in 1971, when the parliament decided that children shall live at home and attend the municipal schools where they live.⁴⁶

Below is a short description of some institutions that have existed for persons with disabilities.

Children and Youth with Cognitive Impairments

Families with children with cognitive impairments were advised to dispose of and forget the child. The then prevailing rational view involved experts taking care of those deemed “not normal”. In “Hemmets läkarebok” (book with medical advice for the home) from 1949, the psychiatrist Hakon Sjögren wrote: “It goes without saying that the idiots need to be taken care of in special institutions. It is not uncommon that their mothers do not want to part from them, but in misguided motherly love wish to keep them at home for as long as possible. Something which, of course, means considerable stress not only for the mother, but for the rest of the environment as well.”⁴⁷

The institution Vipeholm had at most approximately 1,000 “patients” and was made infamous for the so-called Vipeholm experiment. At the end of the 1940s, children

and youth living at the Vipeholm institution were fed sweets in the shape of a special kind of toffee to study what the effect on their teeth would be while not being provided dentist treatment. The experiment showed how sugar causes caries and resulted, among other things, in the advice to only allow children sweets once a week.⁴⁸ The experiment at Vipeholm illustrates how persons with cognitive impairments were used and viewed as individuals without human value. Vipeholm became synonymous with institutional abuse.

The care of persons with cerebral palsy (CP) included lying in bed one’s whole life. A student working extra hours during the summer of 1953 reported huge suffering and sadism: “The care workers rarely put down the leather strap, which they always have on them for disciplinary reasons.” Sweden’s largest mass grave in modern times is located at Norra kyrkogården, a cemetery in Lund, where 560 individuals forgotten during their lives are buried without a name.⁴⁹

The history of schools for children and youth with cognitive impairments is coloured by shifting views on whether they are educable. Already in 1893, there was a public enquiry appointed on the introduction of compulsory school attendance for children with cognitive impairments. The influence came from the implementation of compulsory school attendance for deaf and blind children. The government rejected the enquiry’s proposals on economic grounds – something which also happened to the enquiry of 1920.⁵⁰

46 Persson, Margareta. *Gamla synsätt spökar än – funktionshinder genom tiderna*. Stockholm: Instant Book. 2018. 121,141.

47 Grünwald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009.95.

48 Grünwald, Karl och Olsson, Thomas. *Utan talan – historia i bild från omsorgerna om utvecklingsstörda*. Stockholm: Liber AB. 1997. 68–78.

49 Persson, Margareta. *Gamla synsätt spökar än – funktionshinder genom tiderna*. Stockholm: Instant Book. 2018. 92–93.

50 Grünwald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 123–136.

The Act (1944:477) concerning education and care of “educable retarded” was enacted in 1944, involving – among other things – commitment to school institutions. During the 1950s, special schools for pupils with cognitive impairments were developed under the Act Concerning Special Boarding Schools from 1955. These boarding schools were the primary support measure for children and youth with cognitive impairments, also during the 1960s.

In 1960, around 3,000 “educable” pupils lived in special school institutions, while “severely retarded” children were neither habilitated nor educated. Approximately 6,000 so called “severely retarded” children were without these support services.⁵¹ The county councils started special classes, more children could remain at home, and the number of places in special boarding schools decreased. Further reductions came about when the county councils, in the 1970s, opened school homes, which as a rule consisted of four children sharing a flat or villa. Approximately 1,500 children/youth lived in school homes. Every city with a paediatric clinic was also supposed to have a care home for children. Staff were trained, and physiotherapists, paediatricians, and child psychiatrists were linked to the care homes.

At most, around 6,000 children and youth lived in special boarding schools and care homes for children with cognitive impairments. Around 1970 there were no longer waiting lists for special boarding schools

and care homes, and during the 1980s, these were closed down.⁵²

A legal right to schooling for children with cognitive impairments was regulated under the Care Act (OmsL), enacted in 1968. After that, the special schools were regulated under the Education Act (SkolL), and only then did all children with cognitive impairments have compulsory education. Training schools complemented the special schools, and the concept of “non-educable” was discarded in 1968. Between 1988 and 1996, the municipalities took over responsibility for the special schools. Admission to the special school “without consent” was substituted by admission “on demand”. Parents or guardians were then offered the opportunity to demand schooling for the child according to the curriculum for special schools. Today the school system offers special schools at all school levels, including adult education for persons with cognitive impairments.⁵³

12,300 pupils were admitted to the compulsory special school in the school year 2019/2020. It was an increase of ten percent compared to the previous year. Approximately 4,580 pupils in compulsory special schools attended the program for training schools. A little over 1,530 pupils attended compulsory special school through integrated elementary classes in 2019/2020.⁵⁴

However, attending special schools instead of regular schooling has proved to have long-term negative effects on the ability to gain employment despite many individuals both

51 Grünewald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 123–136.

52 Grünewald, Karl. *Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad*. Läkartidningen. Nr. 44, 2001.

53 Grünewald, Karl. *Från Idiot med medborgare*. Stockholm: Gothia Förlag AB. 2009. 171–190.

54 Skolverket. *Grundsärskolan*. Skolverket. <https://www.skolverket.se/undervisning/grundsarskolan> (Retrieved 2022-12-28).

wanting to and being able to hold down a job. Closer to 80 percent of the pupils leaving special schools are outside of the labour market. Many go from upper secondary special schools to daily activities under LSS, instead of going into the open labour market.⁵⁵

Children and Youth with Visual and/or Hearing Impairments

“De Blindes och Döfstummes Institut” (The Institute for Blind and Deaf-Mute) opened in 1808 and moved to Manilla at Djurgården in Stockholm in 1812. The institute admitted both blind, hearing impaired, and, for a short period, pupils with cognitive impairments. The education focused eventually on pupils with hearing impairments. In the 1870s, more schools for deaf pupils were built. Deaf children got compulsory schooling already in 1889. The first school classes for pupils with hearing impairment were formed in 1922, and the number increased up until the 1970s. The county councils were responsible for the schools for deaf children until 1938, when the national government assumed it. However, Swedish Sign Language was not officially recognised as an independent language until 1981. Bilingual education has been of profound importance for deaf pupils and pupils with hearing impairment concerning opportunities for higher education and career choice.⁵⁶

Pupils who are deaf or have a hearing impairment, as well as pupils with visual and hearing impairment, can nowadays receive bilingual teaching in a sign language environment in a special school, attend school

classes for pupils with hearing impairment, or smaller teaching groups (in Swedish called “hörselgrupper” or “hörselspår”) integrated into the municipal elementary school.⁵⁷

From 1845, the teaching of blind children was provided at “Öfvre Manilla”. The basis for the teaching of blind pupils changed at the end of the 1800s due to the arrival of braille. Compulsory elementary schooling (“folkskolan”) was introduced in 1842, and with that the public’s view of education changed. The national government assumed responsibility for the education of blind pupils and pupils with visual impairments. In 1896, compulsory schooling was introduced for blind children. It was feared that the parents’ poverty or lack of interest would prevent blind children from the opportunity of an education. All children with visual impairments got their education at Blindinstitutet, the institute for the blind at Tomtebodas boarding school.

Braille was taught at Tomtebodas, even to pupils who had some sight. The education was of high quality, but leaving your family to study at a boarding school left scars, according to Ann Jönsson, whom Margareta Persson interviews in her book “Gamla synsätt spökar än” (The Ghosts of Old Attitudes Lingers On). “I was absolutely terrified. I simply do not remember the first period. I also remember that I could not go to sleep after the reading of the compulsory evening prayer. I was so scared of the dark in the big hall.”⁵⁸

Until the 1940s, it was a given that children with visual impairments should be separated from their parents and attend

55 Göransson, Kerstin och Szönyi, Kristina och Tideman, Magnus. *Utbildning och undervisning i särskolan*. Stockholm: Natur & Kultur Läromedel. 2021.

56 Persson Bergvall, Inger och Sjöberg, Malena. *Åratal – ur handikapphistorien*. Stockholm: Handikapphistoriska Föreningen. 2012. 18–19.

57 SPSM. *Döv eller nedsatt hörsel*. SPSM. 2022. <https://www.spsm.se/funktionsnedsattningar/dov-eller-nedsatt-horsel/> (Retrieved 2022-12-28).

58 Persson, Margareta. *Gamla synsätt spökar än – funktionshinder genom tiderna*. Stockholm: Instant Book. 2018. 164.

boarding schools. During the 1950s, people started to consider whether children with visual impairments could be allowed to attend elementary school in their home community. The ideology of integration was formed, and around 1985/1986, the school at Tomtebodavägen was closed down. Today, children with visual impairments attend regular elementary schools in the municipalities.⁵⁹

Children and Youth with Mobility Impairments

Universal elementary school was introduced through a parliament decision in 1842. However, it only applied to children who could get to school unaided and participate in education without special support. Compulsory schooling was introduced in 1882, but did not include disabled children, who hence remained at home without schooling. “Vanförevården” (The Care for Cripples) was introduced during the 1800s, and at the end of the century, the expansion of “vanförestalter” (school institutions for cripples) started. During the first half of the 1900s, school homes were connected to the institutions, where children and youth with mobility impairments could live and attend school. The institutions provided both medical and orthopaedic treatments.

Residents with mobility impairments at the institutions had anything from “hunchback”, CP, MS, polio, and “clubfoot”, to various traumatic injuries. Voices among the residents describe the institutions as places where cruel methods of upbringing left indelible marks.

Hans Fredrik describes Eugeniahemmet like this: “It was a cold, loveless, poor environment with a strong religious character. It was a hard upbringing. You were always suspected of doing forbidden things. The staff group was small, and it was not easy for the ladies to have time for all the children even if they had wanted to. Even the physical environment was poor, with chairs standing along the walls, portraits in gold frames, and a table at the centre of the floor; outdated furnishing even in those days. The toys appeared when the queen came visiting, but only to then disappear again.”⁶⁰

Children with mobility impairments lived and got schooling at, for example, Eugeniahemmet, which was opened in 1879 as an institution for children with mobility impairments. A school and care home for poor, incurable, and disabled children, excluding children with cognitive impairments. Norrbackainstitutet in Solna was founded in 1891 within the framework of the activities of Eugeniahemmet, by the association for aid to the “crippled” and “invalid” in Stockholm. In 1935, it moved to Norrbacka and was formally inaugurated. Norrbackainstitutet conducted medical and rehabilitating activities, as well as schooling and vocational training for children and adults with mobility impairments. All school and boarding activities at Norrbacka ended in 1979.⁶¹

The demand for a place at Eugeniahemmet increased rapidly. Many parents were convinced by their municipality to choose care in an institution even for children as young as 3–4 years, and for the whole school pe-

59 SRF. Skolor och undervisning. Synskadades Museum. 2016. <https://www.srf.nu/om-oss/museet/synskadades-historia/skolor-och-undervisning/> (Retrieved 2022-12-28).

60 DHR. Levande röster i vår historia. Förlag Brevskolan, 1984. 39.

61 Norrbacka & Eugeniahemmets vänner. Välkommen till Föreningen Norrbacka & Eugeniahemmets vännerns egen hemsida på nätet. Norrbacka & Eugeniahemmets Vänner. <https://www.norrbacka-eh.se/> (Retrieved 2022-12-28).

riod. Some remained until adult age to get a vocational education, and some lived there their whole lives. Children and parents rarely saw each other, if at all.⁶²

“This will be your other home for a few years”, mum said.

“But you will stay with me?”, I asked and started to feel insecure about all the things called homework and friends.

“No, I will not,” my mother answered.

“There are kind sisters here that will take care of you. So you will have to promise to obey them and be a nice girl, and you will be good in school. You can show us what you learnt at Christmas already. We will try to come and get you so you can spend Christmas at home.”

Siw Eriksson in her book “Siws liv” (The Life of Siw) on her arrival at Eugeniahemmet in 1946.⁶³

Some parents resisted the request from the doctor to leave their child at an institution and chose to keep them at home or bring them back to the family. Aja Lind writes about Jonas Jacobsson:

“Jonas was born in 1963. When he was three months old, he was found to be paralysed from the waist down. The medical team informed the parents: ‘You do not need to worry – you can leave him here, and we will make sure that someone takes care of him. There are institutions that take care of children like Jonas. He will probably just

be laying in his bed for the rest of his life. Leave him here and go home to your other children.’ The parents: ‘Of course, Jonas should come home again. He is a part of the family, and no matter what type of “handicap” he has, he should be brought up at home

the same way as his brothers.’ Jonas Jacobsson became a target shooter and the best Paralympian male athlete of all time, with 30 paralympic medals and 39 world championship medals.”⁶⁴

Compulsory schooling for all was enacted in 1962. The Act (1965:136) on school homes for certain children with mobility impairments and others meant that the county councils should organise housing with services for pupils with mobility impairments who, for some reason, could not attend the school where they lived. School institutions started to discharge children. In 1969, integration became a concept within school policy, together with a new teaching programme for elementary schools, which meant that disabled pupils should attend ordinary school classes and get individual support there instead.⁶⁵

According to the present school law, all pupils shall get the teaching and aid they need to attend school with good results.⁶⁶ However, there are still four national upper secondary schools for pupils with mobility impairments (so called “RH riksgymnasi-

62 Norrbacka & Eugeniahemmets vänner. Välkommen till Föreningen Norrbacka & Eugeniahemmets vännerns egen hemsida på nätet. Norrbacka & Eugeniahemmets Vänner. <https://www.norrbacka-eh.se/> (Retrieved 2022-12-28).

63 Eriksson, Siw. *Siws liv*. Stockholm: Migra förlag, 2004. 21.

64 Lind, Aja. *Lämna honom här: boken om Jonas Jacobsson, världens främste manliga paralympier*. Sigma Förlag, 2021.

65 Persson Bergvall, Inger och Sjöberg, Malena. *Åratal – ur handikaphistorien*. Stockholm: Handikapp-historiska Föreningen. 2012. 18–21.

66 SFS 2010:800. Skollag.

er”). Their target group is the youth who need adapted teaching, rehabilitation, and/or housing with service, due to comprehensive mobility impairments.⁶⁷

Adults in Institutions

Society’s earliest support services for disabled persons were various types of institutions. During the second half of the 1800s, many institutions were built by private initiative with economic support from the national government or the municipalities. Society did not differentiate between schooling, housing, and care until the 1960s, but had all these functions included within the institutions.⁶⁸

The care of so called “sinnesslöa” (best translated “mentally retarded”, literary means “slow of senses”), in the 1920s and 1930s, consisted of institutions for persons with cognitive impairments and special hospitals/mental asylums for the “asocial” and those “difficult-to-treat”. Stays at these were long-lasting without end dates and meant both incarceration and medical experiments. The length of a stay at an institution could vary, but for most, it was a life-long ordeal.⁶⁹

There was an over-reliance on institutional care in the 1950s. The Act (1954:483) on education and care of certain “mentally retarded” put the responsibility for both schooling and care of persons with cognitive impairments on the county councils. An exception

was made for certain groups, for example persons with cognitive impairments who were deemed “asocial”, “difficult-to-treat”, or “severely retarded”. The national government would remain responsible for the care of these individuals at special hospitals and special care homes.

Every county council had a plan for extensive expansion of care in institutions. In the 1950s, 40 new institutions with, on average, 200 places were built. There were approximately 40 more institutions built in the 1960s and 1970s. During the 1960s, 14,000 persons with cognitive impairments lived at institutions in Sweden. New institutions were built until 1980, when there no longer was a queue for institutional care. At that time, Sweden had approximately 180 institutions.⁷⁰

34,000 places in psychiatric hospitals existed in 1960 for persons with mental illness. Persons with experiences of psychiatric care have, for example, via the Swedish Association for Social and Mental Health (RSMH), testified of inhuman care methods and abuse.

In the middle of the 1970s, approximately 19,000 persons were still incarcerated in around 20 psychiatric hospitals. Forcible commitment of persons with “retardation” on the sole ground that they had a cognitive impairment was no longer allowed. If compulsion was needed, it was only allowed under the laws on coercion existing, for example, within psychiatric care.⁷¹

67 SPSM. Funktionsnedsättningar. SPSM. 2022. <https://www.spsm.se/funktionsnedsattningar/> (Retrieved 2022-12-28).

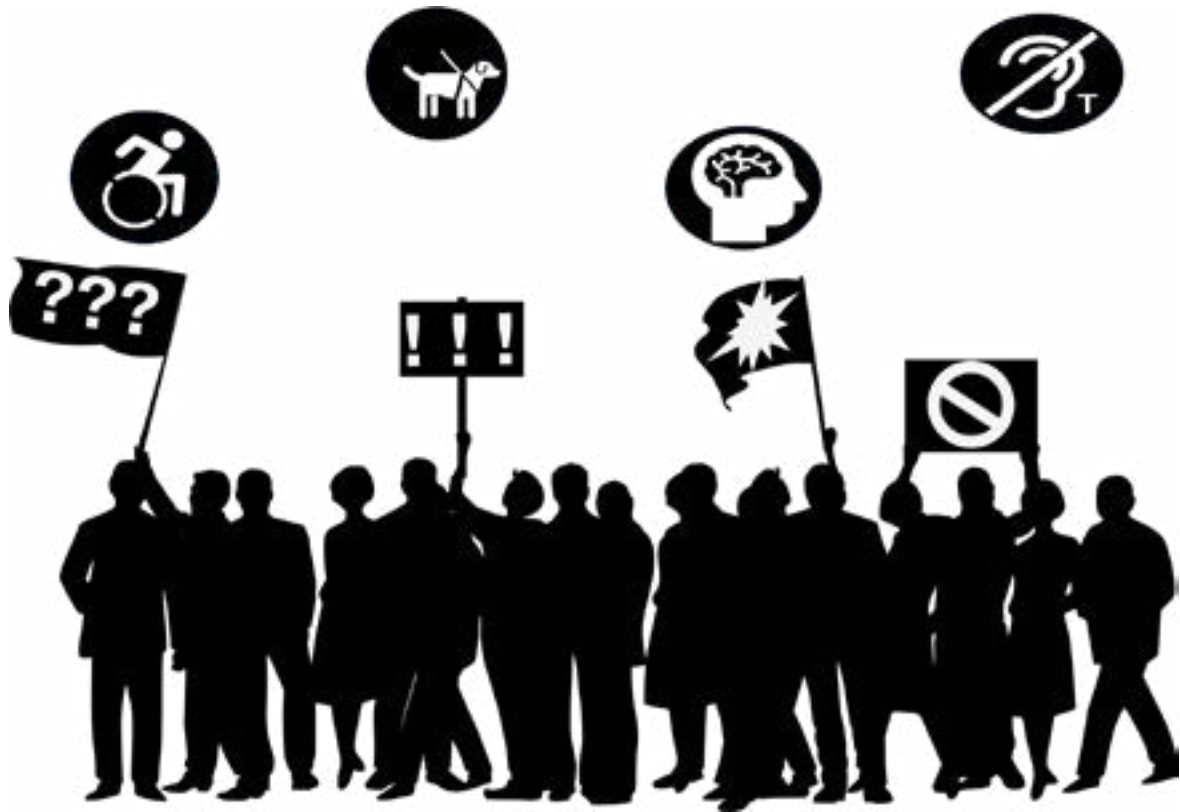
68 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen. 2012.12.

69 Grünewald, Karl. Från idiot till medborgare. Stockholm: Gothia Förlag AB, 2008. 742.

70 Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. Läkartidningen. Nr. 44, 2001.

71 Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. Läkartidningen. Nr. 44, 2001.

The Influence of Disability Rights Organisations



Civil society has long been important for societal change in Sweden, but – “the disability rights movement was for a long time not a natural part of ‘the Swedish popular movements’. My earlier involvement in the labour movement gave me many glimpses of how ‘odd’ the labour movement has viewed disability issues and the disability movement. I often got comments like, ‘You devote yourself to such worthy causes...’ a word you use about something of no concern for yourself...”⁷²

Some disability associations belonged to the earliest popular movements in Sweden, but

most were not founded until far into the 1900s. The organisations have, from the start, had the task of acting as meeting places for persons with experience of living with impairments. However, many organisations developed and came to work for societal change in order to gain increased participation in the community.⁷³ Below are some organisations that have acted to make living conditions for disabled persons better by demanding support and rights and contributing to the closing of institutions.

The Deaf-Mute Association in Stockholm was founded in 1868 with the purpose of acquiring work for its members. The idea came

72 Persson, Margareta. *Gamla synsätt spökar än – funktionshinder genom tiderna*. Stockholm: Instant Book, 2018. 253.

73 Persson Bergvall, Inger och Sjöberg, Malena. *Åratal – ur handikapphistorien*. Stockholm: Handikapphistoriska Föreningen. 2012. 5.

from Berlin, where a deaf-mute organisation had existed since 1848.⁷⁴ The Swedish Association of the Deaf and Dumb was founded in 1922 and covered the whole country. The Swedish Association for the Well-Being of the Deaf was founded in 1921 for persons with hearing impairments. The Swedish National Association of the Deaf (SDR) pursues issues of human rights and democratic rights for deaf persons. The association works for the right to, and the possibility of, using Swedish Sign Language, which is essential for deaf person's participation with equal opportunity in the Swedish society.⁷⁵

Today, the Swedish National Association for Persons with Hearing Impairments (HRF) is Sweden's largest association for persons with hearing impairments and works in the interest of persons with hearing impairments by informing, supporting, and influencing. HRF also accept next of kin, especially parents of children with hearing impairments.⁷⁶

The Blind Association was founded in 1889 and reconstructed in 1976 into the Swedish Association of the Visually Impaired (SRF). SRF works based on the idea of equal value for all human beings, and demands the right to participation and equality in all areas for persons with visual impairments. SRF also wants to create a social community where members can support each other in living an active and independent life.⁷⁷

In 1923, The Peer Association for the Well-Being of Cripples was founded at "Vanförestalten" (The Institute of Cripples) in Gothenburg, and after that, local associations at other school institutions for "crip-

ples" were founded. The part of the association located in Stockholm protested – even from the beginning – against the association's leaders being "icke vanföra" (non-cripples). Pupils at the institution in Helsingborg founded the free-standing association Värnet, which fought for better conditions at the institutions. Helmer Nilsson, who was a member of Värnet already in 1930, recounted: "We thought it was deplorable with curfews in the evenings, compulsory to ask for leave of absence, two compulsory church services per month and saying grace at mealtimes, little pocket money – three kronor (SEK) per month – etcetera. Our struggles succeeded in getting some changes enacted."⁷⁸ In 1965, the name was changed to the National Federation of the Disabled (DHR). Today, the letters DHR stand for Participation (Delaktighet), Power of Action (Handlingskraft), and Freedom of Movement (Rörelsefrihet).⁷⁹

The National Association for Disabled Children and Adolescents (RBU) has existed since 1955. In the 1950s, it was common for teachers to advise parents to admit their children to an institution, where they had to grow up far away from their parents and siblings. Children and youth with mobility impairments were an invisible group in the community and not compelled to attend school. Today, most of these children live at home with their families. RBU means that recognising the children's need for support, rehabilitation, and education is as important today as it was back then.⁸⁰

74 Ramsemar, Erik. Handikapprörelsen växer fram. Brevskolan, 1981. 14–20.

75 SDR. Vårt arbete & handlingsprogram. Sveriges dövas riksförbund. 2022. <https://sdr.org/vart-arbete/> (Retrieved 2022-12-28).

76 HRF. Om HRF. Hörselskadades Riksförbund. <https://hrf.se/om-hrf/> (Retrieved 2023-01-15).

77 SRF. Om oss. Synskadades Riksförbund. <https://www.srf.nu/om-oss/> (Retrieved 2022-12-28).

78 DHR. Levande röster i vår historia. Förlag Brevskolan, 1984. 20–21.

79 DHR. DHR:s historia. DHR. <https://dhr.se/om-oss/dhrs-historia/> (Retrieved 2022-12-28).

80 RBU. Om RBU. RBU. <https://rbu.se/om-rbu/> (Retrieved 2022-12-28).

In 1956, the National Association for Retarded Children (RFUB) was founded. The abuse in the institutions was regarded as unacceptable, and the voices against institutions grew stronger. According to Karl Grünewald, the association became important in the struggle against prejudices, and was an important source of information for the public and the politicians.⁸¹

The association was founded as support to the parents, and the issue of children's possibility to remain in their family home while attending school was dominant. The association journal was a conduit for the voices of parents. They described the care and schooling that their children were offered.⁸² Today, the association is called the Swedish National Association for People with Intellectual Disability (FUB) and it works for the right to a good life for children, youth, and adults with cognitive impairments.⁸³

In 1969, Vilhelm Ekensteen founded the action group/association Antihandikapp (Anti-Handicap). The message of the action group was: "Handicap is to a large extent a consequence of deficits in society. Many handicaps can be eliminated. It is done by changing the society."⁸⁴ Ekensteen's book of polemics "På folkhemmets bakgård" (In the Back-Yard of the People's Home) advocated equal opportunities for disabled persons as early as

1968. The cause should be elevated from care issues to the political debate in the community.⁸⁵ The book was reviewed in the daily newspaper "Göteborgs Handels- och Sjöfartstidning", where it was described as a rebellious book by a "crip". "The author urgently calls for central planning, a concrete target for disability policy. Now, people are improvising ahead, from region to region, but the target is often cloaked in obscurity. The present day's solutions hardly live up to the name: who wants to accept a life in institutions as a solution?"⁸⁶

The thought that the issues should be viewed from a community context, instead of as a care issue, was also the main message of the disability rights movement's first program on disability policy, "Ett samhälle för alla" (A Society for All), which came in 1972. This environment-relative concept of disability has later influenced, for example, the work of the UN. "The Anti-Handicap" movement was critical of society, charity, and the disability organisation's way of working. One of the most important messages was that disability always must be viewed in relation to society.⁸⁷

The Independent Living movement was established in Sweden in 1984, when STIL, The Founders of Independent Living in Sweden (formerly The Stockholm Association

81 Grünewald, Karl. Omsorgsrevolutionen. Tidskriften Intra, 2015. 25.

82 Lind, Judith. Föräldrainflytande och barnets bästa, i Utanförskapets historia. Engwall Kristina och Larson Stig (red.). Lund: Studentlitteratur, 2012. 106.

83 FUB. Om FUB. FUB. 2022. <https://www.fub.se/om-fub/> (Retrieved 2022-12-28).

84 Ekensteen, Vilhelm. På folkhemmets bakgård. Prisma förlag, 1968.

85 Ekensteen, Vilhelm. "På folkhemmets bakgård & Anti-Handikapp". I Den oändliga vandringen – Handikapphistorisk Årsbok 1990. Fingraf, 1990. 103.

86 Ransemar, Erik. Handikapprörelsen växer fram. Brevskolan, 1981. 126.

87 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 42.

of Independent Living), was founded and contributed to the knowledge of the need for self-determination, among other things, by the struggle for the right to personal assistance. STIL, through Adolf Ratzka, introduced personal assistance, and the organisation's pilot project brought the service form to be included in the LSS. The foundation Independent Living Institute (ILI) has existed since 1993 to promote human rights issues for disabled persons.⁸⁸

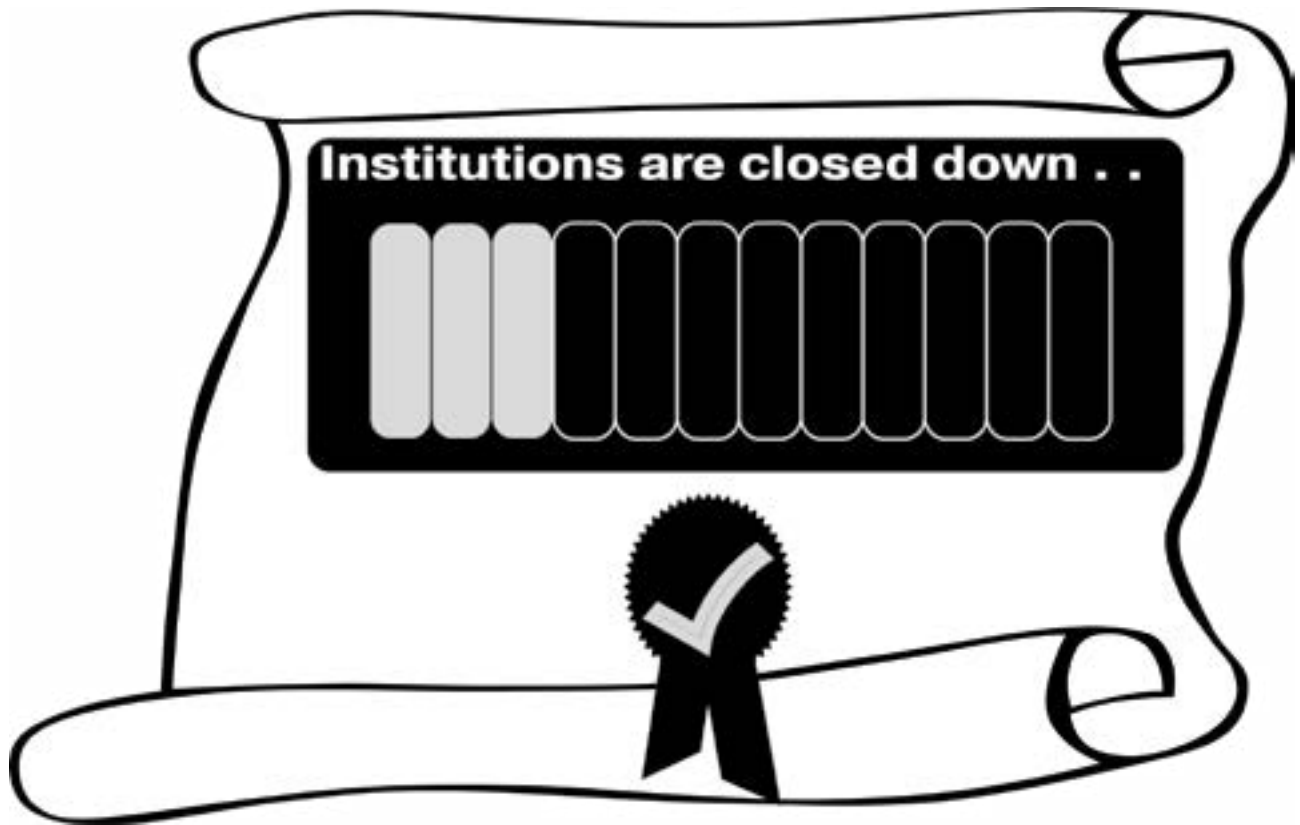
The Swedish Disability Rights Federation is an umbrella organisation and its mission is to be the voice of the united disability movement, against the government, parliament, and national authorities. Its main goal is the implementation of CRPD and to oppose discrimination.⁸⁹ In 2021, the umbrella organisation consists of 49 national disability rights associations. However, there are several large associations which are not part of the umbrella organisation.

The organisations have, from the start, had the task of acting as meeting places for persons with experience of living with impairments. ”

88 ILI. Independent Living Institute (ILI). Independent Living Institute. 2022. <https://www.independentliving.org/> (Retrieved 2022-12-28).

89 Funktionsrätt Sverige. <https://funktionsratt.se/funktionsratt-ratten-att-fungera-i-samhallet-pa-lika-villkor/manskliga-rattigheter/> (Retrieved 2023-01-04).

The Reforms Before Deinstitutionalisation



Reforms involving social services and financing possibilities have been important for implementing deinstitutionalisation. Reforms aimed at disabled persons started to be implemented in the 1940s.

From 1948, regulations on invalid pensions were introduced, leading to the sick benefits being replaced by regulations on early retirement/sick benefits in 1963. Early retirement was transferred from the pension system to the sick insurance in 2003 and was now called sickness benefit (for persons 30–64 years old) and activity benefit (for

persons 19–29 years old). In the 1940s, the Act (1947:529) concerning universal child allowance was enacted. In the 1950s, access to medical treatment and cost-free medicine increased, and national sick insurance was enacted in 1955.

The first social measure for disabled persons, which was not connected to institutions, was the blind allowance in 1934. In 1962, it was replaced by the invalid allowance and was also available for persons with other types of impairments. In 1975, it became the handicap allowance.⁹⁰

In the 1950s, mobility/technical aids

⁹⁰ Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 13–14.

started to develop. Cars were adapted for persons with mobility impairments, and hearing aids were improved. It became possible to receive grants for different aids. The electric wheelchair became a free mobility aid in 1968.

The decision in 1913 to introduce universal pension insurance meant that Sweden became the first country in the world to have social insurance encompassing the whole population (over 67 years of age). The so-called people's pension was enacted in 1948, and the general supplementary pension (ATP) passed in 1960.

Housing allowance was enacted in the middle of the 1930s to support families with children in rented housing, but has since been extended to economically vulnerable households of more family types. Housing supplementary allowance for persons with sickness benefits and activity benefits is provided as a support for high housing costs. The size of the housing and housing supplementary allowance depends, among other things, on income, number of children, housing costs, and the size of the residence.

When disabled persons moved out of the institutions into their own homes, they needed to be able to travel and move around like others. After various local solutions had been tested, the municipalities were granted a national grant for a special transport service from 1975 to 1992, and in 1984, the national mobility service was organised. It was done through a project funded by the Swedish Inheritance Fund.⁹¹ In 1997, laws on special transport services and national mobility services were adopted. Mobility

was for a long time viewed as an issue of mobility aids, and monetary grants were mainly introduced in the 1940s and 1950s to purchase so-called invalid mopeds: three- or sometimes four-wheeled mopeds adapted for drivers with mobility impairments. In 1966, the existing rule on national grants to purchase invalid mopeds was changed so persons with mobility impairments could receive grants to purchase a car and car adaptations if the car was needed for work or studies. This was the first step towards a car allowance in the shape of a national benefit for purchasing and adapting a car.⁹²

The Act (1965:136) concerning school homes for certain pupils with mobility impairments guaranteed housing and care during the compulsory school period for pupils who could not remain in their families and attend a school where they lived. This was due to the schools' inaccessibility and the lack of accessible housing in the home community. Institutions with schooling and rehabilitation in joint premises were built. Persons with comprehensive mobility impairments should be able to continue studying at upper secondary schools or folk high schools with access to individual support.

The county councils and the national government shared the responsibility for the financing of the right to higher education, and the first national upper secondary school for persons with mobility impairments was founded. Persons with mobility impairments would receive schooling, but they also needed access to work, housing, and individual support.⁹³

91 Allmänna Arvsfonden. <https://www.arvsfonden.se/om-allmanna-arvsfonden/arv-som-utvecklar-sverige> (Retrieved 2023-01-04).

92 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapp-historiska Föreningen. 2012. 34–35.

93 SFS 1965:136. Elevhem för vissa rörelsehindrade barn m.fl.

Many persons with comprehensive impairments needed accessible housing and support to live by themselves. There were still thousands of adults with mobility impairments living with their parents or in hospitals or homes for the elderly. The demand for accessible housing and support and services was huge.

In the middle of the 1960s, there was an initiative to build flats with services so that youths could live by themselves. The telethon “Röda fjädern” (The Red Feather) collected money to fund so called Fokushus (Focus Houses) with accessible flats and housing services all over the country. Approximately 250 flats in 14 locations in Sweden were built. Fokushus became a new type of institution providing a housing solution to around 300 individuals. When the collected funds in the Fokus foundation were about to run out, the experiment ended. In 1973, the activities became the responsibility of the municipalities. However, housing with services as a support service developed slowly in most municipalities.⁹⁴

Many people within the existing disability rights movement were critical of the telethon because it was based on the view that the living conditions of disabled persons were a charity issue. The responsibility for accessible and functional housing and necessary support for persons with mobility impairments should rest with the municipalities. There were also critical voices against the building of segregated houses for persons with mobility impairments as it went against the idea of integration and participation in the community. Something which demands accessible accommodations within the ordinary

housing stock and individual support in the community.⁹⁵

The disability rights movement voiced increasingly strong demands for good housing with services in all municipalities. In 1970, the association DHR presented a survey among 350 individuals under the age of 60 living in long-term care facilities – their then only housing option. The survey showed deeply undignified living conditions. More than half of those concerned had to go to bed before seven o’clock at night, and only 40 percent had their own room.⁹⁶

In the middle of the 1980s, the parliament report “Bo på egna villkor” (Living on Your Own Terms) resulted in a parliament decision on housing conditions for elderly, long-term sick, and disabled persons. The decision meant that “all humans, irrespective of the need for support, help and care, have the right to a residence with good accessibility and good standard of space and equipment in an environment which provides conditions for active participation in the community.”⁹⁷

Housing with services became a permanent support service within the municipality. The flats had services around the clock and were intended for persons with comprehensive mobility impairments. They should be integrated into ordinary housing areas but be connected to each other to enable joint service. The service was provided by a joint staff group, which had its premises within the unit. At the enactment of LSS in 1994, the residents were given the option to apply for personal assistance and, with that, gain more influence over their lives. The municipalities then momentarily chose to close housing with services provided by a joint staff group.

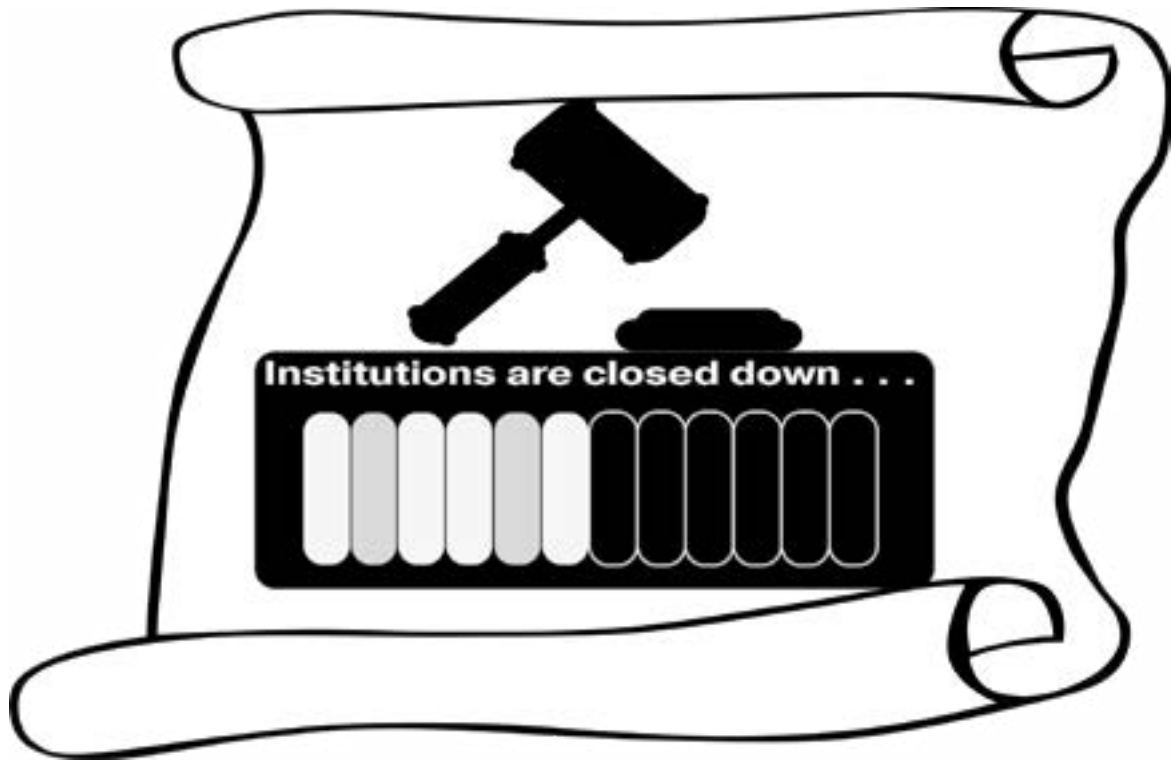
94 Erika Wermeling <http://erikawermeling.se/stiftelsen-fokus/> (Retrieved 2023-01-04).

95 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikaphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 28.

96 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikaphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 29.

97 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikaphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 29.

Laws Concerning Deinstitutionalisation



Below, laws essential for the process of deinstitutionalisation are presented.

The care act (1967:940) was enacted on the 1st of July 1968 to facilitate a planned move, out of institutions into instead living in the community with support. Responsibility was transferred from the government to the county councils. Adults with cognitive impairments living at home got the right to daily activities with social training and meaningful tasks in 1968. The parents got care relief to cope with having their grown-up children at home until the county councils had finished building group homes.⁹⁸

However, isolation and alienation remained for persons with special and comprehensive needs. In the middle of the 1970s, all county councils had a central institution for persons with “retardation with various complications”. Persons with “mild retardation with social adaption problems” were committed to the national special hospitals.⁹⁹

The Social Care Act, SoL, (1980:620) was enacted in 1982, including, for the first time, a special paragraph concerning municipal support to disabled persons. The municipality social welfare board shall act so that individuals, who, due to physical, mental, or

98 SFS 1967:940. Lag angående omsorger om vissa psykiskt utvecklingsstörda

99 Grünwald, Karl. Omsorgsrevolutionen. Tidskriften Intra, 2015. 210.

other reasons encounter considerable difficulties in their daily life, will get the opportunity to participate in the community and live like others. The social welfare board shall contribute to the individual receiving meaningful occupation and living in a manner adapted to their special support needs, as well as organise housing with special services.¹⁰⁰

*The Care Act (1985:568)*¹⁰¹ was enacted on 1st July 1986 as a revision of the law of 1967 and became an important reform for disability policy. Approximately 8,000 individuals at the remaining 30 care homes for children and 130 care homes for adults were to move out into the community. The law ruled a stop for admissions to care homes and special hospitals. The county councils and the private owners must formulate a plan for closure.

The care act did not state a final date for the closure of the institutions, and the process was slow. There were also responsible decision-makers who had a negative view on the change, and the number of institutions was approximately 200 when the shut down started.¹⁰²

New regulations concerning housing construction from 1985 ruled that public mortgages also included the construction of group homes. Every resident within a group home should have their own flat of at least 40 square meters. The result was that the waiting lists for admission to care homes for adults finally ended at the beginning of the 1980s.¹⁰³

The Act concerning Support and Service for Persons with Certain Functional Impairments, LSS (1993:387), was enacted on 1st January 1994 due to the work of the parliamentary committee on disability of 1989. The law put further pressure on the closing of institutions. LSS replaced the care act of 1985 and this meant that the target group was expanded. Hence, the law now included everyone with comprehensive impairments causing considerable difficulties in daily life, partly due to the introduction of the new service of personal assistance.

The Act on closing special hospitals and care homes (1997:724) was enacted on 1st November 1997 and included a definitive standpoint for deinstitutionalisation. The reason for enacting the law was that many care home owners did not share the existing ideology of closing institutions, so a final date for the process had to be fixed. In 1997, there were still 1,000 persons with cognitive impairments in a total of 52 institutions. To speed up the process, a compulsory regulation to complement the LSS was needed.¹⁰⁴ The law dictated that existing special hospitals should immediately be closed down in 1997 and that all residents of institutions should move to suitable accommodations in the community no later than 2000.

All residents of institutions received a decision from their home municipality, which would be responsible for their support. The municipalities should show individual plans for every concerned person to the Nation-

100 SFS 1980:620. Socialtjänstlag.

101 SFS 1985:568. Lag om särskilda omsorger om psykiskt utvecklingsstörda m. fl.

102 Grünewald, Karl. Omsorgsrevolutionen. Tidskriften Intra, 2015. 210.

103 Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. Läkartidningen. Nr. 44, 2001.

104 Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. Läkartidningen. Nr. 44, 2001.

al Board of Health and Welfare (SoS). The plan should describe the individual's future accommodation. From the 1st January 2000 an extension had to be approved by the SoS if the plan on future housing got delayed.¹⁰⁵ Some individuals had lived in institutions for shorter periods, but many had spent their whole lives being institutionalised, in some cases for more than 70 years. Now, everyone had to move to their own flats, most of these connected with smaller group homes for a maximum of 5–6 persons.

In 1995, a radical psychiatric reform was implemented. Persons remaining within the

institutional mental care system should move out to flats or group homes. The municipalities were responsible for daily activities, home care, and social gathering premises. Personal advisers to provide support in everyday life were introduced. Despite belonging to the law's target group, persons with mental impairments found it hard to receive support under the LSS.¹⁰⁶ After the closing of the psychiatric hospitals, the individuals' periods of acute sickness should be treated with shorter periods of care within the medical services' psychiatric clinics until outpatient care is possible.

Some individuals had lived in institutions for shorter periods, but many had spent their whole lives being institutionalised... ””

105 SFS 1997:724. Lag om avveckling av specialsjukhus och vårdhem.

106 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 31.

Closing of Institutions



In the 1960s, the path to deinstitutionalisation started to form. This was a western trend, and the oppressive structures of the institutions were described by Goffman and Foucault.

Goffman coined the term total institutions, where all parts of the inmates' lives were subordinated to the institution. This had a strong influence on the view of institutions – on those who had power and executed control, but also on those who were subordinated and controlled. The expansion of national social insurance, pensions, and benefits for disabled persons was important for the process of deinstitutionalisation.¹⁰⁷

The conditions within the institutions began to be debated and criticised. Reports in the 1960s of vulnerability, violence, and medical experiments signalled the need for change.

The authorities' inspection reports became public and a vital leverage for revival. Crucial for the closing of the large institutions was, according to Karl Grönwald, the existence of a political will, that the parliament's right to legislate trumped local self-determination, and the fact that national authorities had the right to issue regulations and rules concerning deinstitutionalisation. The national finances were also a requisite for decisions on various forms of necessary support for disabled persons and their next of kin.¹⁰⁸ The politicians Bengt Lindqvist (Minister of Social Affairs 1985–1991) and Bengt Westerberg (Minister of Social Affairs 1991–1994) held an essential importance in implementing the deinstitutionalisation and reforming support in the community.

The parliamentary committee on disability of 1965, and a survey on the situation of

107 Ringsby Jansson, Bibbi. "Institutionsavveckling och sen? Om boende och vardagsliv i nya former för personer med utvecklingsstörning." I *Handikapp – synsätt principer perspektiv*. Tideman Magnus (red.).

108 Grönwald, Karl. *Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad*. *Läkartidningen*. Nr. 44, 2001.

disabled persons, led to more reforms and the closing of the institutions for individuals with mobility impairments.¹⁰⁹

The so-called normalisation principle, which involves the right to normalised living conditions for disabled persons, became a leading concept. The principle was formulated in the middle of the 1960s by Bengt Nirje, and it has influenced disability policy both in Sweden as well as other countries. The principle is based on the equal value of all individuals. Care in the community should be a priority, and everything possible should be done to avoid admission to an institution. Group homes for adults should be a priority before care homes. The benchmark number of residents in a school home for children/youth and group home for adults should be four. Dwellings should be part of ordinary housing developments.¹¹⁰

Persons with cognitive impairments should be offered an environment like others of the same age. Support should be provided to parents wanting to keep their children at home. Disabled persons should be accommodated and live like others, which means new demands on support and services from society. One type of support was a care allowance to enable the parents to keep their disabled children at home. If the family could not cope, a foster home should be the first alternative, not a care home. If adults could not manage to live in their own flats, the care homes should be organised as similar to an

ordinary home as possible, with individual rooms in small units on the ground level to enable contact with the outer world.¹¹¹

The Care Act of 1968, regulations for building housing from 1985, and the revised Care Act from 1986 concerning persons with cognitive impairments and others were important for closing large institutions and developing new care forms. A paragraph concerning the municipality's responsibility for disabled persons was part of the Social Care Act (SoL) of 1982.¹¹²

The parliamentary committee on disability of 1989¹¹³ and its conclusions and proposals led to the enactment of the Act on Support and Service (LSS) in 1994 and the final closing of institutions in 2000. Disabled persons should be viewed as full citizens and have the right to live in the community with support from the rights within the LSS. The rights enhanced by the LSS should be based on the individual's right to self-determination and was meant to provide the necessary support for disabled persons to live in their own homes and/or move out of institutions. The Swedish Independent Living movement had a vital influence on the organisation of the new support measure of personal assistance. Together with housing with services and daily activities, personal assistance became the most sought-after support service.¹¹⁴

When LSS was enacted, the main responsibility for the care of persons with cognitive impairments was transferred from the coun-

109 Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. *Läkartidningen*. Nr. 44, 2001.

110 Nirje, Bengt. *Normaliseringsprincipen*. Lund: Studentlitteratur AB, 2003.

111 Riksdagen SE/RA/323051 Handikapputredningen 1965.

112 SFS 1980:620. Socialtjänstlagen.

113 SOU 1992:52. 1989 års Handikapputredning. Ett samhälle för alla – Handikapputredningens slutbetänkande.

114 SFS 1993:387. Lag om stöd och service till vissa funktionshindrade.

ty councils to the municipalities. However, the county councils were still responsible for closing institutions unless they agreed otherwise with the municipality where the institution was located. The medicalised view of disabled persons now started to change, and the transfer of responsibility away from the county councils with their responsibility for medical services, to the municipalities was of symbolic importance. A disabled person was no longer to be viewed as a patient, but as a citizen in their home municipality. Only the responsibility for a more specialised medical care such as specialised rehabilitation centres, rehabilitation treatment, mobility/technical aids, and interpretation were left within the regional administration.¹¹⁵

A change in attitude of disabled persons and their needs was required for disabled persons to become citizens with a right to full participation. Children and youth with comprehensive impairments were to remain with their families, and adults with comprehensive impairments were to live in their own home with the support of personal assistance or in a housing unit with services. Good examples where disabled persons lived included in the community helped to change attitudes and increase support for deinstitutionalisation.

Disability rights associations played an important role for political change. An inclusive community requires pressure to provide necessary support services and an accessible and functional society.

***An inclusive community
requires pressure to provide
necessary support services
and an accessible
and functional society.*** ”

Support and Service to Disabled Persons



The support and service guaranteed under the laws are a prerequisite for disabled persons being able to live a self-determined life. The laws will ensure that they and their families get access to care, support, and services. The support services are to contribute to life in the community with equal opportunity as others. The individual – or their legal guardian – needs to apply for the support.

Supported Decision-Making

How a person receives support to make decisions is regulated by law.

The Act Concerning Trustees and Legal Guardians (1994:1433) was enacted on 1st July 1995 and regulates support to individ-

uals needing help with economic and legal rights. It can, for example, involve support to apply for medical treatment and care, managing the personal economy, or contacts with public authorities. A person who has a trustee still has the right to decide over their money and property and conclude agreements. If a trustee is not enough, a district court can appoint a legal guardian for individuals not capable of managing themselves or their assets. A legal guardian is an enforced measure. This means that the district court can decide to appoint a legal guardian without the individual's agreement. An individual who is assigned a legal guardian loses the right to conclude agreements or manage their money. This instead becomes the responsibility of the legal guardian.

The Act Concerning Future Power of Attorney (2017:310) was enacted on 1st July 2017 and regulates the possibility of a power of attorney to somebody who will have the right to manage the economy and legal rights in the future, for example, due to sickness. This can be an alternative to a trustee or legal guardian.

Three Laws on Medical Services, Support, and Service

Necessary support services are important to prevent admission to group homes and institutions. Sweden has three laws that regulate medical services, support, and service. The Health and Medical Services Act (2017:30), the Social Care Act (2001:453) and the Act concerning Support and Services to Certain Persons with Functional Impairments (1993:387). These are described below.

The Health and Medical Services Act, HSL (2017:30) was enacted on 1st April 2017 and includes goals and guidelines for all health and medical services. It describes the medical services that the region, municipality, and other providers of medical services must provide. HSL regulates support services to medically prevent, investigate, and treat sickness and injuries. It regulates rehabilitation and access to technical aids. HSL also regulates emergency medical care. Individuals must be residents in Sweden to have the right to planned medical services.¹¹⁶

The Social Care Act, SoL (2001:453) was enacted on 1st January 2002 and establishes the main goal of the social welfare services to promote people's economic and social security, equality of living conditions, and ac-

tive participation in the community. Under SoL, the social welfare board in the municipality is responsible for certain groups in society, namely: children and youth, elderly, disabled persons, persons with addictions, and persons who take care of or support a next of kin. The social welfare services shall be focused on releasing and developing individuals' and groups' resources, and the activities shall be based on respect for individuals' self-determination and integrity.

The municipality is not only responsible for its residents, but also has the ultimate responsibility for anyone staying within its area. SoL contains specific paragraphs on the right to extra support and aid for disabled persons. The municipality's social welfare board shall work to enable individuals with comprehensive difficulties due to impairments to participate in the community and live like others. The municipality shall provide information about the social welfare administration's support services and approach those who may need support. The municipality shall also offer support to disabled persons' next of kin.

Before LSS was enacted in 1994, all municipal support services for disabled persons were provided under SoL, excluding support under the Care Act for persons with cognitive impairments. LSS is a complementary law, and disabled persons not covered by the law can instead apply for support under SoL. It is also possible to receive support under both SoL and LSS simultaneously.¹¹⁷

The Act Concerning Support and Services to Certain Persons with Functional Impairments, LSS (1993:387) was enacted on 1st January 1994. The purpose of the LSS was to

116 SOSFS 2017:30. Hälso- och sjukvårdslagen.

117 SFS 2001:453. Socialtjänstlagen.

provide disabled persons who belongs to its target group with rights to the support needed to be able to live good and self-determined lives unless the needs are not satisfied by other means. The support services under LSS shall contribute to good living conditions. The right to a good and self-determined life includes, for example, the opportunity to a home of your own, to have a family, to work, to study and/or have a meaningful occupation. Persons with cognitive impairments (who belong to the category one or two of the target group – see below) also have the right to daily activities. Individuals shall be able to participate in the community and partake of cultural and leisure activities with equal opportunity as others. LSS is a rights base law, which means that the support measure cannot be limited due to the lack of resources.

Support services under LSS must be based on the following quality criteria: self-determination, influence, integrity, participation, accessibility, a holistic view, and continuity. Individuals must be directly involved in the organisation of the support. The municipality must consider what is best for the child when providing support services within the LSS for children. The child shall be given information and the opportunity to offer their opinions according to their age and maturity.

The individual applies for support from the municipality's social welfare administration at their registered domicile, except for the support measure of advice and other personal support, which is applied for at the region's health and medical services/rehabilitation centers, as well as national assistance allowance which is applied for at the Swedish social insurance administration.

The Three Target Groups of LSS

LSS does not cover all disabled persons. To be eligible for support services within LSS, an individual must belong to one of the following three categories in the law's target group:

1. Individuals with cognitive impairments, autism, or autism-like conditions.
2. Individuals with considerable and permanent intellectual impairments due to a brain injury acquired when adult and caused by external violence or bodily illness.
3. Individuals with other comprehensive permanent physical or mental impairments, which clearly are not caused by normal ageing, and result in difficulties to unaided manage daily life activities such as getting dressed, preparing food, moving, or communicating with the environment.

On the contrary, from categories 1 and 2, category 3 is not guided by diagnoses. The assessment of whether an individual belongs to category 3 is based on the person's difficulties in everyday life.¹¹⁸

Some support services within the LSS have certain limitations. Category 3 of the target groups does not have the right to daily activities under LSS. Personal assistance is not granted after the age of 65, but individuals who have personal assistance before the age of 65 will keep the right to the hours they are granted when turning 65. Personal assistance is also not granted to individuals living in special housing with a staff group providing services.

In total, approximately 75,800 disabled persons had municipal support services according to the LSS in October 2020. Unlike the reductions in the national assistance, an increasing amount of disabled persons re-

118 SFS 1993:387. Lag om stöd och service till vissa funktionshindrade.

ceive municipal support services according to the LSS. The number has increased by 22 percent since 2010.¹¹⁹ On top of these, support services from the region for advice and support and the national assistance allowance from the national social insurance administration are provided.

Ten Different Support Services according to LSS:

LSS' ten support services shall provide the necessary support for disabled persons to live like others. Certain support services are providing support to the individual's family.

Advice and other personal support. Both the disabled person and their next of kin can receive advice and support from varying expert functions organised by the Swedish regions.

Personal assistance. In order to have the right to personal assistance, the individual must be in need of support with so called "basic needs". These are considered being personal hygiene, meals, dressing and undressing, communication, and/or support needs which demand extensive knowledge of the individual's impairment. When personal assistance is granted, it also includes the right to assistance with other needs such as household chores, leisure activities, and associating with friends and family. If the basic needs are less than 20 hours per week, the application should be reviewed by the municipality. If the basic needs are more than 20 hours per week, the application should go to the National Social Insurance Administration. Personal assistance is not granted if the individual lives in housing with services.

Accompanying services. An accompanying attendant facilitates participation in leisure

and cultural activities, such as: meeting friends, participating in civic associations, or practising sports activities.

Contact person. A contact person acts as a fellow human being/friend when an individual lacks social contact. It is someone to socialise and do activities with according to preferences and interests.

In home respite services. Relatives and next of kin of disabled persons can receive relief to, for example, do tasks outside the home or take time off and relax. Respite services can be available regularly or on an acute basis.

Short term stays outside the home. This support concerns the need for temporary stays outside the family in a short-term home or short term support family, either regularly or for acute needs. A short-term stay can also take the form of a camp or summer holiday activity. The goal is that the individual will get a change of environment and recreation while the next of kin gets time off to rest.

Short term stays outside the home for pupils over 12 years of age. This service covers supervision of youth with comprehensive impairments who need to stay in leisure homes or community youth centres in connection with the school day or during holidays.

Foster families or housing with special services for children or youth. Caregivers can apply for housing with special services for children. The support measure involves either group homes for children or a family home. At the end of 2020, 874 children and youth were granted housing with special services for children under LSS, 60 of them were living in foster families.

¹¹⁹ Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/s00401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02).

Housing with special services for adults or other specially adapted dwellings. The support measure “housing with special service” must, according to the law, include housing with special services for adults or other specially adapted dwellings for adults under 9 § 9 LSS.¹²⁰ Other specially adapted dwellings do not include permanent staff. Instead, support and services will be provided through other support services such as home care, housing support or a personal assistant. Housing with special services for adults are dwellings with access to care, support, and service. It can be group homes or service dwellings.

Dwelling in a group home can be offered to individuals with such extensive needs for supervision and care that round the clock staff is necessary. Group homes consist of a smaller number of flats gathered around communal places. A permanent staff group is available to cover the support needs of the residents.

Service dwellings consist of a number of flats with access to service by a permanent joint staff group, which can be contacted around the clock. The staff is although not necessarily in direct connection to the dwellings. The flats are adapted to the individuals’ needs and often gathered in the same or connected buildings. Therefore, service dwellings are a compromise between a self-determined individual dwelling and dwelling in a group home. Living in group homes is the most common support measure under 9 § 9 LSS (concerning housing). In October 2020, the number of adults granted housing with special services was 28,592, and 634 indi-

viduals were granted other specially adapted dwellings for adults.¹²¹

Daily activities. Daily activities are support services for persons of working age belonging to categories 1 and 2, for example. persons with intellectual impairments, autism, autism-like conditions, or a brain injury acquired as an adult. Daily activities are granted in the cases where the individual lacks paid work and is not enrolled in education.

The size and organisation of daily activities have been subject to huge changes after the closing of the institutions. The large day centres have been converted into several smaller units. More and more daily activities have professional or special directions, such as cafés, restaurants, and artistic activities. More individuals with daily activities attend adult education and are trainees in businesses. More vocational training is needed since many who attend daily activity centres want a “real job” with a salary.¹²²

The table on the next page contains the number of granted support services under LSS between 2010–2020 in the municipalities (rounded values).¹²³

On 1st October 2020, there were 75,800 persons receiving at least one municipal service measure according to the LSS. Approximately 89 percent of these were persons with cognitive impairments, autism, or autism-like conditions. The most common service measure was daily activities.¹²⁴ Persons receiving only advice and other personal support from the region or only personal assistance through the national assistance allowance are not part of this group.

120 SFS 1993:387. Lag om stöd och service till vissa funktionshindrade.

121 Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/s00401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02). Table 8.

122 SFS 1993:387. Lag om Stöd och Service till vissa funktionshindrade.

123 Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/s00401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02). Table 5b.

124 Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/s00401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02). Table 4.

Table 5b

Insats	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
1. Advice and other personal support	5,100	4,700	4,500	4,300	4,300	4,400	4,100	3,000	2,100	1,400	900
2. Personal assistande	3,600	3,800	3,900	3,900	4,100	4,300	4,600	4,900	5,100	5,200	5,400
3. Accompanying services	9,300	9,200	8,700	8,500	8,400	8,300	8,000	7,700	7,500	7,300	7,000
4. Contact person	19,500	19,500	19,600	19,400	19,500	19,500	19,400	19,300	19,100	18,700	18,000
5. In home respite services	3,400	3,400	3,400	3,500	3,600	3,800	3,800	3,900	4,000	4,000	4,000
6. Short term stays outside the home	10,000	9,900	9,700	9,600	9,600	9,700	9,600	9,400	9,300	9,100	8,800
7. Short term stays outside the home for pupils over 12 years of age	5,200	5,000	4,800	4,500	4,500	4,400	4,400	4,400	4,500	4,600	4,500
8. Foster families or housing with special services for children/youth	1,400	1,300	1,200	1,100	1,000	1,000	1,000	1,000	900	900	900
9. Housing with special services for adults or other specially adapted dwellings	23,400	23,900	24,400	25,000	25,800	26,500	27,100	27,800	28,200	28,700	29,200
10. Daily activities	30,200	31,100	32,000	32,400	33,800	35,300	36,600	37,500	37,800	38,300	39,000
Total number of support services	111,100	111,800	112,200	112,200	114,600	117,200	118,600	118,800	118,600	118,100	117,800

Laws on Housing Adaptation and Public Transport

A prerequisite of living in your own home is access to support services in everyday life, such as accessible housing and transport. These are regulated under the following laws:

The Act Concerning Home Adaptation Allowance (2018: 222) regulates allowance to adapt a disabled person's own housing and provides an opportunity for a self-determined life in one's own home. The municipalities are responsible for granting allowances to adapt and restore accommodations for all.

The Act Concerning Special Transport Services (1997:736) was enacted on 1st January 1998 and regulates permits for special transport services for persons with comprehensive difficulties of unaided mobility due to permanent impairment.

The Act Concerning National Special Transport Services (1997:735) was enacted on 1st of January 1998 and regulates that the municipality, under certain conditions, must cover transport costs for travel to another municipality for persons having to travel in a specifically costly manner due to comprehensive and permanent impairments.

The Acts Concerning Mobility and Other Technical Aids. The right to mobility and other technical aids is regulated under several laws. The county councils (regions), as principals for medical services, are obligated by law to offer the technical aid a disabled person needs to manage everyday life and/or, as part of, care and medical treatment. When prescribing mobility/technical aids, various laws, ordinances, and regulations come into force depending on where the responsibility for the aid lies.

The Act Concerning Car Allowance (2010:1745, 2019/20:107) Car allowance can be granted to persons under 65 with permanent impairments and comprehensive mobility difficulties who have difficulties using public transport. The car must also be needed to have a laid job, enrol in vocational education, or participate in occupational rehabilitation while receiving activity support or rehabilitation benefits. Car allowance can also be granted to parents or guardians of a child with impairments which cause comprehensive mobility difficulties resulting in difficulties using public transport. Car allowance consists of varying support to buy a car and adaptations, among other things.

Personal Assistance – Part of the National Social Insurance System

The law which provides the right to personal assistance has been an important part of the reforms connected to the closure of the institutions. The new support measure, personal assistance, became a right when LSS was enacted on 1st January 1994. In connection with the LSS-reform, the national assistance allowance for personal assistance was regulated under the Act Concerning Assistance Allowance, LASS (1993:389). LASS remained in force until 2011, when the regulation of national personal assistance was incorporated as a support measure under the Social Insurance Code, SFB (SFS 2010:111).

The purpose of the assistance allowance is to provide persons with a right to personal assistance due to comprehensive and permanent impairments with direct payment, which enables them to organise the assistance in a manner adapted to their individual needs. Personal assistance is an indi-

vidually organised support in the daily life, which can enable a person to move out of a group home and into their own home.

National assistance allowance can be granted for basic and other personal needs if the time needed with assistance for the basic needs exceeds 20 hours per week. If a person needs more than 20 hours of personal assistance with basic needs per week, they can have a right to assistance allowance under chapter 51 SFB. The National Social Insurance Agency assesses, decides, and pays the national assistance allowance.

To have a full picture of the development within personal assistance, statistics on the national assistance allowance and personal assistance granted by the municipalities are required. The national assistance allowance is decided and paid by the Swedish Social Insurance Agency. Personal assistance under LSS for persons with less than 20 hours of basic needs per week is decided and paid by the municipality where the individual is registered as a resident. Over time, the number of decisions on national assistance allowance has decreased from 16,000 persons in 2015, to 13,867 in December 2020. At the same time, the number of decisions on municipal personal assistance has increased to a total of 5,379 persons in October 2020. Most of these are found in the age group 23–64. The average number of granted assistance hours is generally higher within the national assistance allowance, since the individual must be in need of assistance for the so called basic needs of more than 20 hours per week.¹²⁵

The Right to Personal Assistance

The national policy regarding personal assistance in Sweden was strongly influenced by

125 Socialstyrelsen. Insatser och stöd till personer med funktionsnedsättning – Lägesrapport 2020. Stockholm: Socialstyrelsen, 2020. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-3-6686.pdf> (Retrieved 2023-01-02). 73–74.

a pilot project on personal assistance, which was started and carried out by STIL within the Stockholm municipality during the years 1987–1989. STIL is a part of the international Independent Living movement. The experiences from the project influenced the content of the assistance reform enacted in 1994.

Before 1994, support services were organised within the municipal elderly care even for younger disabled persons. Disabled persons lived in their own flats with support from home care services or in institutional cluster housing/housing with services with a local staff group.

Life before personal assistance is described below by Adolf Ratzka:

“Neglecting the dimension of self-determination in service quality reflects the attitude on the part of professionals, administrators, and politicians that people with extensive disabilities have only simple needs, that somebody else easily can interpret and anticipate. Preconceived notions about our needs and preferences are evidence of a still widespread paternalism and can become self-fulfilling prophecies that limit our growth as human beings:

Children with extensive disabilities who live in residential institutions learn fast that asking for assistance too often or at the “wrong” times can have its consequences in terms of resentment or even retaliation by the staff. In the institution where I lived between the ages 17 to 22, I learned to get by by limiting my needs and by not showing any anger. From my experience, this training at an early age over long periods can change personality traits and create adults who appear cheerful and grateful, but have difficulties in forming opinions of their own, in being assertive and clear about their expectations. This outcome, in turn, reinforces the common prejudice that disabled people are friendly and harmless, malleable, and in need of protection.

For example, in the institution where I lived for five years, I had to go to bed at 8 pm because only at that time were there enough staff on duty to put all those who needed help to bed.”

Personal assistance was developed within the Independent Living movement and is a service form defined in the UN general comment number 5 to the article 19 of the CRPD. Personal assistance is intended support that is controlled by the user and provided by a person chosen by the assistance user. The organisation of personal assistance can vary, but there are certain criteria, according to the definition of the general comment and the Independent Living movement, that will separate assistance from other forms of support (text below from the general comment number 5, section 16d):

“Funding for personal assistance must be provided on the basis of personalised criteria and take into account human rights standards for decent employment. The funding is to be controlled by and allocated to the person with disability with the purpose of paying for any assistance required. It is based on an individual needs assessment and upon the individual life circumstances. Individualised services must not result in a reduced budget and/or higher personal payment.

The service must be controlled by the person with disability, meaning that they can either contract the service from a variety of providers or act as an employer. Persons with disabilities have the option to custom design their own service, meaning design the service and decide by whom, how, when, where and in what way the service is delivered, and to instruct and direct service providers.”

Personal assistance is a one-to-one relationship. Personal assistants must be recruited,

trained and supervised by the person granted personal assistance. Personal assistants should not be “shared” without the full and free consent of the person granted personal assistance. Sharing of personal assistants will potentially limit and hinder the self-determined and spontaneous participation in the community.

Personal assistance is to allow for self-management of the service delivery. Persons with disabilities who require personal assistance can freely choose their degree of personal control over service delivery according to their life circumstances and preferences. Even if the employer liability are contracted out, the person with disability always remains at the centre of the decisions concerning the assistance; the one to whom any inquiries must be directed and whose individual preferences must be respected. The control of personal assistance can be exercised through supported decision-making.

In 2020, close to 14,000 persons in Sweden received national assistance allowance for their personal assistance. Almost one thousand private and public service providers offer personal assistance. The Swedish law on personal assistance is an example of demand-driven services, since it creates a market for personal assistance by enabling the users to buy their own services or hire their own assistants based on the granted number of assistance hours. A sum equivalent to the cost of their current number of assistance hours is paid out every month to the assistance user.

Life with personal assistance is described below by Adolf Ratzka:

“Like everybody else, people with disabilities are all different. What we do have in common, what we share with other human beings, is the need to be recognized for who we are, to belong, be respected and loved, the need to realize our innate potential. For this we need to live and be included in the community, with the same degree of self-determination in every-day life and life projects that our non-disabled brothers and sisters, friends and neighbours take for granted.

I need assistants who help me do all that I would have done by myself if I weren't disabled: get bathed and dressed, do my share of the family household, drive my car, go to work, hang out with friends, travel, fix the house, do gardening. For all of this I need assistance from people who are good at what they are doing, people who like to work for me. I have to do the recruiting; I need to train and supervise them. I need to be the boss because I know best what I want to do with my life.”¹²⁶

126 Ratzka, Adolf. Self-determination for Persons with Extensive Disabilities through Direct Payments for Personal Assistance. Independent living institute. 2017. <https://www.independentliving.org/docs7/Self-determination-direct-payments.html> (Retrieved 2023-01-17).

What Was the Result? The Aftermath of Deinstitutionalisation?



Fear of Reinstitutionalisation

The decision to close the institutions was partly anticipated, but also received with insecurity and worry. Doctors and other personnel at then existing special hospitals protested against the decision to close large institutions where approximately 1,000 “difficult to care for” persons were placed. The staff deemed that these persons needed hospital care. The personnel of the institutions felt anxiety and insecurity about their future employment conditions. There were also decision-makers who viewed care homes as the organisation which so far proved to “with-

out a doubt provide the best opportunity for some meaningful and genuine life for persons with cognitive impairments” and wanted to save “the small, well-functioning care homes”.¹²⁷

Family and close next of kin of persons with cognitive impairments feared society’s support services would not be enough. Around 50–80 percent of next of kin were antipathetic to the change preceding the closing of the institutions. There was also fear of how persons with cognitive impairments would be treated, risk for trafficking, drugs, and loneliness in the community. In the fol-

¹²⁷ Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. Läkartidningen. Nr. 44, 2001.

low-up, the number of next of kin satisfied was around 80 percent. That is: as many as were negative before the change. The next of kin appreciated that their relative had now gotten a better life. Above all, the “personal housing, the telephone, and the exclusive meeting space that provided possibilities for spontaneous visits and promenades” were appreciated.¹²⁸

The closure of the large institutions had not been possible without the contemporary decision on LSS. For the closing of the institutions, it was crucial that necessary support and service was regulated under the rights-based law LSS with ten types of support services, which the individual can apply for depending on their needs. Access to necessary support services for individual needs is essential for the possibility of living included in the community like others.

In his historic description of the institutional era, Karl Grünewald writes: “The institutional era will in the future appear as a strange era of our cultural heritage. It has provided us with far-reaching experiences that must not be forgotten.”¹²⁹

The closing of the large institutions started at the end of the 1970s. The most intensive closing period of institutions for adults took place over a 20 years period between 1980 and 2000. The institutions had residents from varying parts of Sweden. At the closing, these people had a right to civic registration in the municipality where the institution was placed. The consequences were that some municipalities with large institutions ended up with high costs for support services.

Responsible decision-makers and politicians were worried about how the change would affect the future costs of the municipalities. A national system for equalisation of costs connected to LSS was adopted in 2004. The system of cost equalisation is based on the costs for LSS and the respective municipalities.¹³⁰

The responsibility for medical services was changed, so the special doctor was replaced by health and medical services in the regular primary care system. When the parliament decided to make the municipalities principals for the services under the care act in 1993, the exception was that the county councils would keep the responsibility for expert services in the form of rehabilitation. Caring for the youngest children with very extensive support needs created problems when closing the care homes for children. The children remained in hospitals until the county councils organised housing with special services (pupil’s homes) with enhanced medical supervision. The closing eventually was implemented, and the children, in consultation with the parents, had housing alternatives outside the care homes.¹³¹

Persons who moved out after living their whole life in an institution often had a hard time imagining what life in their own flat or in a group home would be like. For example, furnishing and decorating their own home for the first time was a new experience. The next of kin realised that their relatives settled under the new conditions, and life in their own home became calmer and more comprehensible than in the large institutions.

128 Grünewald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 187.

129 Grünewald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 472.

130 SFS 2008:342. Lag om utjämning av kostnader för stöd och service till vissa funktionshindrade. Förordning SFS 2008:776.

131 Grünewald, Karl. *Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad*. Läkartidningen. Nr. 44, 2001.

We turn to Gustav, 80 years:

“You have furnished your own flat in a group home after a whole life in different institutions. What makes you the happiest in your new home? Gustav: I am most happy to have a door of my own and have my own name on my on it for the first time in my life. I am also happy to have my own post box for my mail. I have never had that before.”¹³²

Many evaluations have been done on the closing of the institutions for adults. In conclusion, it is shown that the individuals who moved to group homes received more individualised care, felt safer, looked for and found more contact, needed fewer medicines and fewer hospital visits, and slept better at night. Evaluations of individuals with challenging behaviour showed improvement for more than half of the group, even if a smaller part had the same problems in the group homes.¹³³

The last persons to move out from institutions were those with challenging behaviour and persons in need of extensive sup-

port. This was the case despite the positive experiences of many other disabled persons moving from large institutions to small group homes, where the environment became small-scale, calm, and understandable. Fewer persons in small units affected the continuity positively. An evaluation of several individuals with severe behavioural problems was conducted. These people had lived in institutions almost all their lives and then a couple of years in group homes. The findings showed a decrease in personality disorders and deviant behaviour.¹³⁴

“Per was one of the last who moved from a large institution to a group home in the center of a big city. Per had a challenging behaviour and needed recurrent surgeries and treatment due to swallowing different loose items. After moving into his own flat in a small group home for four individuals, his challenging behaviour immediately stopped, and Per started to enjoy city life with the support of a limited number of persons he knew and who knew his needs.”¹³⁵

¹³² Karlsson, Riitta-Leena; from her work with Deinstitutionalisation in the 1990s.

¹³³ Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. *Läkartidningen*. Nr. 44, 2001.

¹³⁴ Grünewald, Karl. Omsorgsrevolutionen. *Tidskriften Intra*, 2015. 213.

¹³⁵ Karlsson, Riitta-Leena; description from Per from her work with Deinstitutionalisation in the 1990s.

Current Situation After Deinstitutionalisation

Today, persons with various types of impairments live in regular housing with their families and with the possibility to apply for support under SoL and/or LSS. Creating an accessible, universally designed, and functioning society with access to education, work, and leisure is currently the biggest challenge for the future. Housing with special services for children and adults is a right according to LSS. The support measures can only be granted if the individual or their trustee/legal guardian or parents applies for the support.

Persons with cognitive impairments, autism, and acquired brain injury are still the main group applying for housing of varying group types, where a staff group provides the support. Individuals who, due to impairments, cannot or dare not live in regular housing available on the housing market have the right to support under SoL and/or LSS.

Decisions on housing in a group home have dominated the municipalities' decisions on housing with special services according to LSS. In October 2020, more than 30,000 children and adults were granted housing with special services. Only 634 adults were granted "other specially adapted housing", which gives the possibility to organise daily life with the support of individual support services such as personal assistance.¹³⁶

Families who are not granted personal as-

sistance for their children and cannot manage the situation with available support services have to apply for housing with special services for children and youth within LSS. Children's homes according to LSS means placing them in foster families or group homes.

In October 2020, a total of 874 children were granted housing with special services for children and youth. 60 children/youth lived in foster families. Housing with special services for children and youth has decreased by 36 percent since 2010. However, many municipalities feel there is a future need for the support measure since the assistance allowance has been severely cut for children and youth with impairments, complex needs, and insufficient support at home.¹³⁷

The number of recipients of the national assistance allowance has continued to decrease during 2020 and amounts to just under 13,900 individuals. Compared to the year before, the number of individuals with national assistance allowance has decreased by 300.¹³⁸

The development is worrying and threatens the possibility of living in an individual home for many.

Group homes with 4–6 flats can, according to the general comment number 5 to article 19 of CRPD, be viewed as institutions in comparison to living in your own home and be included in the community.¹³⁹ The decisive difference between a group home and

136 Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/s00401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02). Table 8.

137 Socialstyrelsen – Insatser för personer med funktionsnedsättning Lägesrapport 2021. Stockholm: Socialstyrelsen, 2021. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7327.pdf> (Retrieved 2023-01-03).

138 Försäkringskassan. Indikatorer för att följa utvecklingen av assistansersättningen 2021. Stockholm: Försäkringskassan, 2021. https://assistanskoll.se/_up/akoll_pdf/Forsakringskassan-rapport-maj2021.pdf (Retrieved 2023-01-03).

139 Myndigheten för delaktighet. Konventionen om rättigheter för personer med funktionsnedsättning Allmän kommentar nr 5 om ett självständigt liv och att vara inkluderad i samhällsgemenskapen. Stockholm: MFD, 2020. <https://www.mfd.se/contentassets/10cbb4a4f8e34299beb96d965c77e8fb/2020-2-allman-kommentar-5-sjalvstandigt-liv-inkluderad-i-samhallsgemenskapen.pdf> (Retrieved 2023-01-03).

a self-determined life in your own home is that the first case includes a joint staff group while the other involves individual support, which increases the individual's self-determination.

Adjustment of staff and working methods have been a challenge for many group homes in Sweden. It includes enabling a disabled person to participate and become part of the community after living their whole or a large part of their lives in an institution. Switching from group support to individual support has been one of the most important changes in moving out of institutions. According to the CRPD, this requires adequate staffing and working methods that consider the individual's wishes and respect for self-determination.

Quality standards required according to the LSS have been important for designing new accommodations and prevented the building of new, large institutions. In LSS's preparatory texts, it is emphasised that the number of residents in group homes should be small: the group homes should include 4–5 residents, with a maximum of 6. Every flat – with a minimum of 40 square metres – must have a kitchen and a bathroom. In addition to this, the group home must have communal spaces. A group home shall not be institutionally tinged, and it must be located in regular housing areas.¹⁴⁰

Although, group homes are seldom a temporary housing solution, but are frequently permanent. There is a risk that individuals who once moved into a group home remain

there indefinitely despite their need and wish to move to more self-determined housing.

The expansion of group homes and service dwellings continues as they are applied for according to LSS. Access to accessible and usable housing at a reasonable cost in the regular housing stock is a condition for disabled persons having access to individual living arrangements.

In 1995, a large reform within mental health care was implemented. Individuals remaining within the mental health institutions were to move out into their own flats or group homes. The municipalities were given responsibility for providing occupation, housing support, and places where these individuals could meet.¹⁴¹

After the closing of the mental institutions the out-patient care for persons with mental illness has not had the extensive legal support as for persons with other impairments within LSS. Belonging to LSS's target group is assessed restrictively, and the municipalities have not to a large extent used the support services within the LSS for persons with mental impairments. Partly due to the lack of knowledge on the rights LSS within the municipality's social-psychiatry units. Support services have exclusively been granted under the social care act, SoL, which involves lower quality standards. For example, housing has often been provided in the form of individual rooms in a communal environment with corridors and hygiene facilities shared by many individuals.

140 SOSFS 2002:9. Socialstyrelsens föreskrifter och allmänna råd om bostad med särskild service för vuxna enligt 9 § 9 lagen (1993:387) om stöd och service till vissa funktionshindrade.

141 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapp-historiska Föreningen. 2012. 31.

The employer organisation The Swedish Association of the Local Authorities and the Regions (SALAR) has said the following:

“Increased flexibility in varying forms of housing must always be based on self-determination and participation to achieve a positive outcome. That the residents in housing with services have more influence on the choice of the dwelling is a condition for efficient support. The prevalence of cohabitation is increasing as well as the occurrence of residents in LSS-dwellings wanting to climb the housing ladder or move to housing with services with a different composition than that of the resident group. If the municipalities work together with individuals, next of kin, and interest groups, both individual wishes and municipal housing planning can benefit from increased flexibility.”¹⁴²

What are the Numbers?

LSS regulated the right to housing with special services in the form of group homes or specially adapted homes at the same time as the decision to close the institutions was given a definitive final date: the turn of the millennium. Housing with services in the form of group homes has increased steadily and is, after daily activities, the most granted support measure according to LSS.

The following statistics describe the development of different housing types before and after the decision of deinstitutionalization:

In 1960 approximately 14,000 individuals lived in large institutions, and in 1970 approximately 10,090 individuals lived in institutions and 2,630 in pupils' homes/school homes.

In 1970: 500 individuals lived in group homes

In 1980: 3,200 individuals lived in group homes

In 1990: 8,200 individuals lived in group homes

The act Concerning Support and Service to Certain Persons with Functional Impairments (LSS) was enacted in 1994

In 1995: 13,000 individuals lived in group homes and service housing according to LSS

In 1997: 1,000 individuals remained living in 52 institutions

In 2000: 15,800 individuals lived in group homes and service housing according to LSS¹⁴³

Final date for deinstitutionalisation was 1/1/2000

In 2010: 23,400 adults and 1,400 children/youth lived in housing according to LSS¹⁴⁴

In 2020: 29,226 adults and 814 children/youth lived in housing according to LSS¹⁴⁵

Over ten years, the costs for support services within LSS have increased by an average of 2,5 percent per year. During the same period, the costs for support services for disabled persons within SoL have increased by 3 percent per year. According to the National Board of Health and Welfare (SoS), the increased costs within the municipalities are primarily mirrored by an increase in support services. The distribution of costs between

142 Sveriges Kommuner och Regioner. Stöd för prognos av boende enligt LSS. Stockholm: SKR, 2020. https://skr.se/download/18.4829a209177db4e31aa26f4e/1615197367613/Rapport_%20Prognos_av_boenden_%20enl_%20LSS_%20slutv.pdf (Retrieved 2023-01-03). 52.

143 Grünewald, Karl. Från idiot till medborgare. Stockholm: Gothia Förlag AB. 2009. 451–470.

144 Socialstyrelsen. Personer med funktionsnedsättning – insatser enligt LSS år 2010. Stockholm: Socialstyrelsen, 2011. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/statistik/2011-4-18.pdf> (Retrieved 2023-01-03). Table C.

145 Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/s00401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02). Table 8.

LSS and SoL in the municipalities has been stable over time; 80 percent come from LSS, and 20 percent from SoL.¹⁴⁶

The Importance of the Convention on the Rights of Persons with Disabilities (CRPD)

The CRPD meant a paradigm shift for the whole world. Disabled persons were now to be viewed from a rights-based perspective and not from a perspective of care. The social model, where societal obstacles cause disability, would now influence social policy, legislation, and treatment of disabled persons.¹⁴⁷ The UN general assembly adopted the CRPD on 13th December 2006. Sweden ratified the convention, which came into force in January 2009, and Sweden is therefore obligated to implement the rights recognised in the articles of the convention.

Definitions and Principles according to the CRPD

In article 2 of the CRPD, several important definitions are made. The definitions below have central importance to understanding the content of the convention's articles from a Swedish perspective.

Communication includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-speech, and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology. Language includes spoken and signed languages and other forms of non-spoken languages.

Discrimination based on disability means any distinction, exclusion, or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment, or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.

Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

Universal design means the design of products, environments, programmes, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities when they are needed.¹⁴⁸

Article 3 of the CRPD states the convention's principles:

- a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons,
- b) Non-discrimination,
- c) Full and effective participation and inclusion in society,

¹⁴⁶ Socialstyrelsen. Insatser och stöd till personer med funktionsnedsättning – Lägesrapport 2020. Stockholm: Socialstyrelsen, 2020. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-3-6686.pdf> (Retrieved 2023-01-02). 32.

¹⁴⁷ Crock, Mary och Smith-Khan, Laura och McCallum, Ron och Saul, Ben. The Legal Protection of Refugees with Disabilities – Forgotten and invisible? Sydney: Edward Elgar Publishing Limited, 2017. 19–22, 21.

¹⁴⁸ Ds 2008:23. FN:s konvention om rättigheter för personer med funktionsnedsättning.

- d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity,
- e) Equality of opportunity,
- f) Accessibility,
- g) Equality between men and women,
- h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.¹⁴⁹

The UN Committee on the rights of persons with disabilities, which monitors the convention's implementation, develops the understanding of its rights through the general comments.

According to article 4 of the CRPD, disabled persons' situation must not decline.¹⁵⁰ The CRPD-committee has criticised Sweden on several issues where they mean that Sweden does not live up to human rights recognised by the convention. The content in this publication intends to emphasise crucial aspects of the disability policy from the deficits existing in Sweden today.¹⁵¹

Article 19 of the Convention (CRPD) and Housing

Does living in group homes and housing with special services – the communal forms of housing that have replaced the large institutions – live up to the demands in article 19

of the CRPD? The CRPD-committee's general comment number 5 to article 19 clarifies that segregated housing with an un-proportional number of disabled residents who must share a common environment shall not be allowed. The general comment is clear on disabled persons' right to decide which services they need and what daily activities they want to take part in. Institutional support services that segregate individuals or limit the right to self-determination are in breach of the rights recognised by article 19. This applies not only to large institutions, but also to smaller group homes and even institutionally organised home care.¹⁵²

Everyone has the right to their own home, meaning living conditions which provides possibilities for a self-determined life and enables individual integrity to be preserved. Support services in the form of special services and adaption of the physical environment are necessary if this right shall include all disabled persons.

The lack of choice and control distinguishes an institution with living conditions characterised by institutional elements such as:

- Life segregated from the community,
- Loss of control over decisions in daily life,
- The compulsion to share assistants (or other staff),

149 Ds 2008:23. FN:s konvention om rättigheter för personer med funktionsnedsättning. Artikel 19.

150 Ds 2008:23. FN:s konvention om rättigheter för personer med funktionsnedsättning. Artikel 4.

151 Regeringen CRPD/C/SWE/CO/1 Nummer 2020:2, Kommittén för rättigheter för personer med funktionsnedsättning – Sammanfattande slutsatser och rekommendationer.

152 Myndigheten för delaktighet. Konventionen om rättigheter för personer med funktionsnedsättning Allmän kommentar nr 5 om ett självständigt liv och att vara inkluderad i samhällsgemenskapen. Stockholm: MFD, 2020. <https://www.mfd.se/contentassets/10cbb4a4f8e34299beb96d965c77e8fb/2020-2-allman-kommentar-5-sjalvstandigt-liv-inkluderad-i-samhallsgemenskapen.pdf> (Retrieved 2023-01-03).

- Service is organised in paternalistic ways meaning someone else decides what is best for the disabled person,
- None or limited influence over who will assist (or offer other services) you,
- Loss of the right to choose where and with whom you live,
- Rigid routines that do not consider individual needs or wishes,
- Identical activities are arranged by persons in a position of power for the group they have power over.¹⁵³

The CRPD recognises equal rights for disabled persons to live in the community with the right to choices equal to others. The government must take effective and suitable services to facilitate full enjoyment of this right and full inclusion and participation in society, for example, by making sure that:

- Disabled persons have the possibility, on equal conditions as others, to choose their domicile, where and with whom they want to live, and not be forced to live in special housing.
- Disabled persons have access to a series of services within the home, housing, and other community support services, including individual aid needed to support living and being included in society and prevent isolation and segregation from the community.
- Public services and buildings are accessible on equal conditions for disabled persons and are responsive to their needs.¹⁵⁴
- It is an important task to monitor to what extent communal housing types in Sweden implement and live up to the life qualities recognised by article 19 of the CRPD.

Decisions on housing in a group home have dominated the municipalities' decisions on housing with special services according to LSS. ”

153 Berg, Susanne och Linder, Ola. Rätten till ett självbestämt liv i samhällsgemenskapen: en essä om grunderna i Funktionsrättskonventionens artikel 19 och Independent Livingideologin. Artikel 19 som verktyg. 2019. <https://lagensomverktyg.se/2019/essa-artikel-19-och-ideologin/> (Retrieved 2022-12-28).

154 Ds 2008:23. FN:s Konvention om rättigheter för personer med funktionsnedsättning. 126.

Swedish Disability Policy

The Swedish disability policy is based on the CRPD, Agenda 2030, the European convention, and Swedish laws. On the proposal from the government in 2017, the Swedish parliament decided on a national goal for disability policy, and the government decided in December 2021 on a new strategy for systematic monitoring of the national goal 2021–2031.¹⁵⁵ The national goal of disability policy is to achieve equality in living conditions and full participation in society for disabled persons. Swedish policy shall contribute to increased equality and respect for the rights of the child. To achieve the national goal, focus must be on four areas:

- The principle of universal design,
- Existing deficiencies in accessibility,
- Individual support and solutions for individual self-determination,
- Preventing and counteracting discrimination.¹⁵⁶

According to the parliament's decision, the starting point for the disability policy shall be the principle of universal equality and equal rights. National, local, and regional authorities have a joint responsibility to ensure that disabled persons have good health, economic and social security, and that individuals are given better chances for self-determination.

Laws and monitoring of their implemen-

tation are important tools to improve living conditions for disabled persons. Health and medical services, education, and support and services are regulated under the Health and Medical Services Act (HSL), the Education Act (Skoll), and the Social Care Act (SoL). The Act concerning Support and Services for Certain Persons with Functional Impairments (LSS) is a law that regulates social rights for persons with comprehensive needs and was the law that provided conditions for the final closure of the institutions.¹⁵⁷

A national agency, the Health and Social Care Inspectorate (IVO), monitors the health and medical services and society's support services for disabled persons. The monitoring focuses on the disabled person's ability to speak for themselves, the individual's participation, the right to self-determination, and the ability to live a self-determined life.¹⁵⁸

The participation of the disability rights organisations in promoting the Swedish disability policy is an important part of the democratic process at the national, regional, and local levels. Many associations receive government funding. The associations have an important role in monitoring that rights are implemented without cutbacks, and create support services that respect human rights and prevent the development of new institutional support services.

155 Regeringen. Strategi för systematisk uppföljning av funktionshinderspolitiken under 2021–2031. Stockholm: Regeringen, 2021. <https://www.regeringen.se/4aaadf/contentassets/cf8af503cbbc499894549da09ea685af/strategi-for-systematisk-uppfoljning-av-funktionshinderspolitiken-under-2021-2031.pdf> (Retrieved 2023-01-03).

156 Proposition 2016/17: 188. Nationellt mål och inriktning för funktionshinderspolitiken.

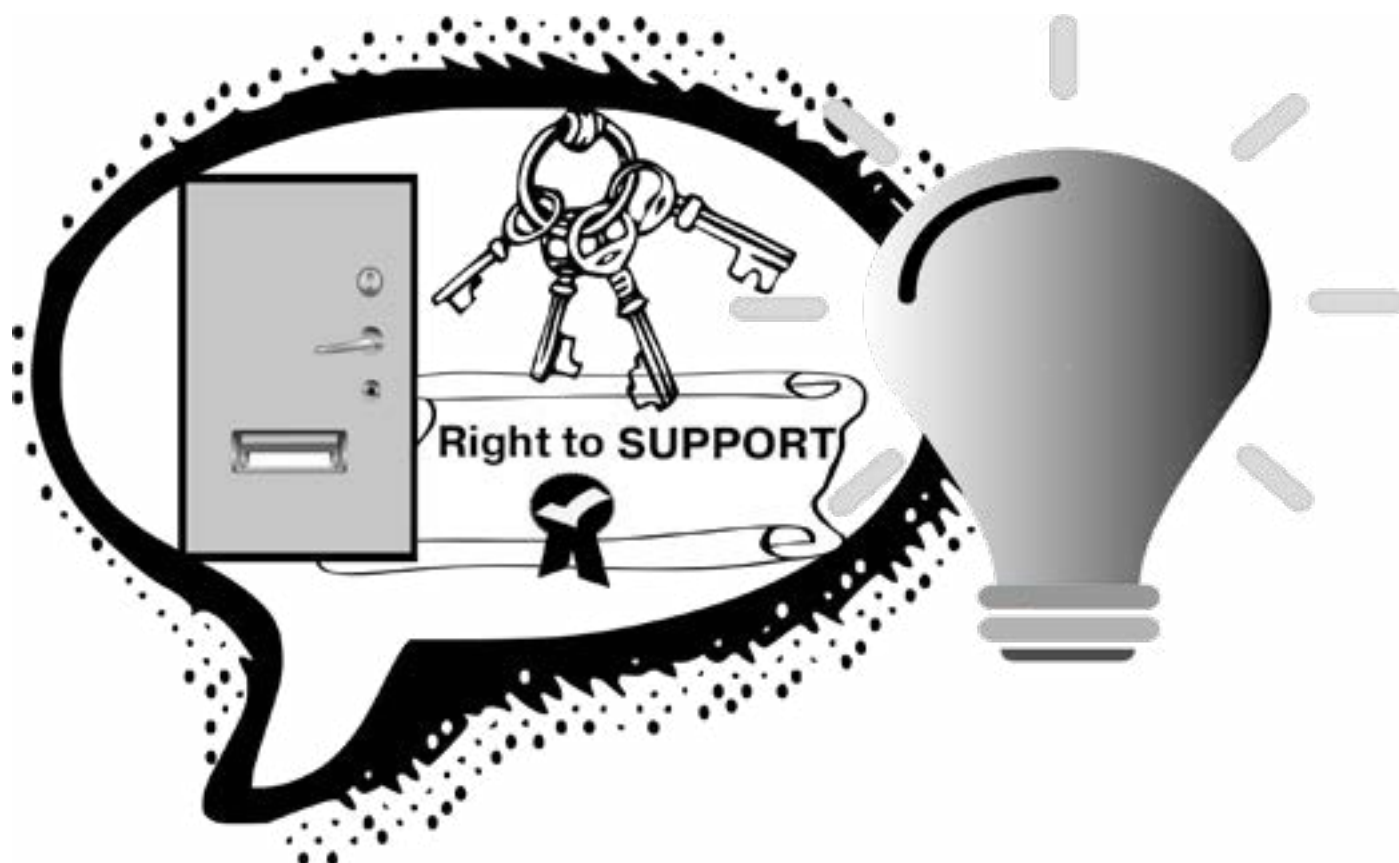
157 SFS 2017:30. Hälso- och sjukvårdslag. SFS 2010:800. Skollag. SFS 2001:453. Socialtjänstlag. SFS 1993:387. Lag om stöd och service till vissa funktionshindrade.

158 Inspektionen för vård och omsorg. IVO. www.ivo.se (Retrieved 2023-01-03).

The Independent Living Institute (ILI) and other disability organisations suspect that the number of individuals living in group homes is increasing. Due to that, a follow-up of the area within the systematic monitoring promised by the government for September 2021 is desirable. What is the situation today considering the cutbacks within the personal assistance service?

According to the parliament's decision, the starting point for the disability policy shall be the principle of universal equality and equal rights.

Conclusions for the Future – What Have We Learned?



Even if Sweden formally has closed the large institutions, many disabled persons lack self-determination in daily life and opportunities to participate in the community. Institutional housing forms need to be complemented with individual housing solutions and personal support to create conditions for a self-determined life with equal opportunities as others, according to the CRPD.

The general comment number 5 of article 19 of the CRPD emphasises that:

- All humans have the freedom to choose, the right to live self-determined, and be included in the community.
- Fundamental human rights and freedoms are not satisfied in institutions.
- Support must be based on respect for individuals' inherent dignity.¹⁵⁹
- Deficits That Need to be Remedied

¹⁵⁹ General Assembly 2006: 61/106. Convention on the Rights of Persons with Disabilities. https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A_RES_61_106.pdf (Retrieved 2023-01-09).

The UN CRPD-committee has criticised Sweden for several instances of deterioration in the support services for disabled persons. There are several areas where the implementation of rights for disabled persons is lacking in Sweden.

Also, Sweden has not acted on the recommendations given by the CRPD-committee in 2014. According to the Swedish Disability Rights Federation Association, none of the recommendations has been fully remedied. The development of the right to live self-determined has regressed contrary to the recommendation of sufficient resources for personal assistance.

The CRPD-committee asks questions based on the reporting from Sweden, and the questions concern almost every article of the CRPD. For example on how the rights have been incorporated in Swedish law, monitoring of the rights within the municipalities, access to the justice system, and how the disability rights organisations are involved in the work.¹⁶⁰ The committee has called for information on services under, among others, the following articles, which concern issues crucial to preventing a re-institutionalisation:

Children with Disabilities (Article 7)

The committee has called for information on decisions to open group homes for disabled children that, according to reports, municipalities have made, on how many children have been affected by these decisions and how their right to family life is respected and promoted.

Living Independently and Being Included in the Community (Article 19)

The committee has asked for information on which services are taken to ensure that disabled persons are granted sufficient economic support to live self-determined in the community, and which criteria that qualifies for personal assistance. The committee has also requested information on which services are provided so disabled persons can choose their domicile, on equal conditions as others, where and with whom they will live. Also, the committee wants information on which measures are taken to ensure that the municipalities speedily implement decisions on individual support.

Participation in Cultural Life, Recreation, Leisure, and Sport (Article 30)

The committee has called for information on the national strategy to protect the right to participate in leisure, sports, and cultural activities inclusively and to what extent austerity measure has affected this right.¹⁶¹

Risk of Reinstitutionalisation

A survey by the National Board of Health and Welfare shows tendencies of group homes being built containing more flats than the number of residents per group home regulated by the LSS. Authorities and interest groups are strongly aware of the need to monitor the quality of housing for disabled persons to counteract tendencies of institutionalisation.¹⁶²

There is a lack of knowledge on the background of – and work with – closing of the large institutions (which causes opinions to

¹⁶⁰ Ds 2008:23. FN:s Konvention om rättigheter för personer med funktionsnedsättning.

¹⁶¹ Förenta nationerna. Förteckning över problem före inlämning av Sveriges kombinerade andra och tredje periodiska rapporter. Förenta nationerna, 2018. <https://funktionsratt.se/wp-content/uploads/2018/10/FNs-fr%C3%A5gelistap%C3%A5-svenska.pdf> (Retrieved 2023-01-03).

¹⁶² Socialstyrelsen – Insatser för personer med funktionsnedsättning Lägesrapport 2021. Stockholm: Socialstyrelsen, 2021. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7327.pdf> (Retrieved 2023-01-03).

be voiced suggesting “rational solutions”, increasing the number of the disabled persons living together in larger units to lower the costs of society’s support services). Many of today’s political decision-makers lack knowledge of the history of the poor living conditions and prevalence of violence and abuse in the institutions.

As shown by Karl Grünewald’s: “Opinions can swing, and memory of past injustices fade away. After some generations, there is no longer anyone remembering the background of current rights and they are, perhaps, even disputed.”¹⁶³

In budgetary discussions, proposals for cutbacks are constantly given. Several support services according to LSS have been subject to cutbacks by responsible authorities. Municipal guidelines for the varying support services have been restricted. There are examples of residents in housing with special services who have not had their individual needs assessed, and hence not being granted a contact person or accompanying services. The number of individuals given these services according to LSS has decreased by 51 and 61 percent each. Persons with visual impairments or persons who are deaf-blind have, for example, more difficulties getting access to accompanying services according to LSS.¹⁶⁴

The number of recipients of the national assistance allowance has since 2015 decreased by 2000 individuals. From a little over 16,000 persons in 2014, to a little more than 14,000 in 2019. Slightly less than half of these 2,000 people consists of children and youth between the ages of 16–19, and the largest decrease has been in the age span 0–6, which has reduced by over 70 percent. Changes in law and legal precedents have affected the number of individuals with assistance allowance. The changes have resulted in fewer individuals being granted assistance allowance than before. Concerning the number of approved applications for assistance allowance, there has been a decrease from a little more than 1,000 individuals in 2014, to a little more than 300 in 2019.¹⁶⁵ Alongside legal governance, indirect governance of activities can also exist through documents not formally claimed as regulating.¹⁶⁶

A decrease in national personal assistance has increased municipal personal assistance according to LSS; from 3,550 persons in 2010, to over 5,200 in 2019.¹⁶⁷ In total, 5,379 individuals had municipal personal assistance according to LSS in October 2020.¹⁶⁸

Since implementing the LSS-reform, several investigations have involved changes in the right to personal assistance.¹⁶⁹ Decreasing opportunities for personal assistance increases the risk of reinstitutionalisation.

163 Grünewald, Karl. Omsorgsrevolutionen. Tidskriften Intra, 2015. 13.

164 Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/soo401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02).

165 Försäkringskassan. Rapport – Analys av minskat antal mottagare av assistansersättning. Stockholm: Försäkringskassan, 2020. <https://www.forsakringskassan.se/download/18.3a5418591814e228e441155/1657122938547/analys-av-minskat-antal-mottagare-av-assistansersattning-svar-pa-regeringsuppdrag-dnr-001381-2020.pdf> (Retrieved 2023-01-03). 9.

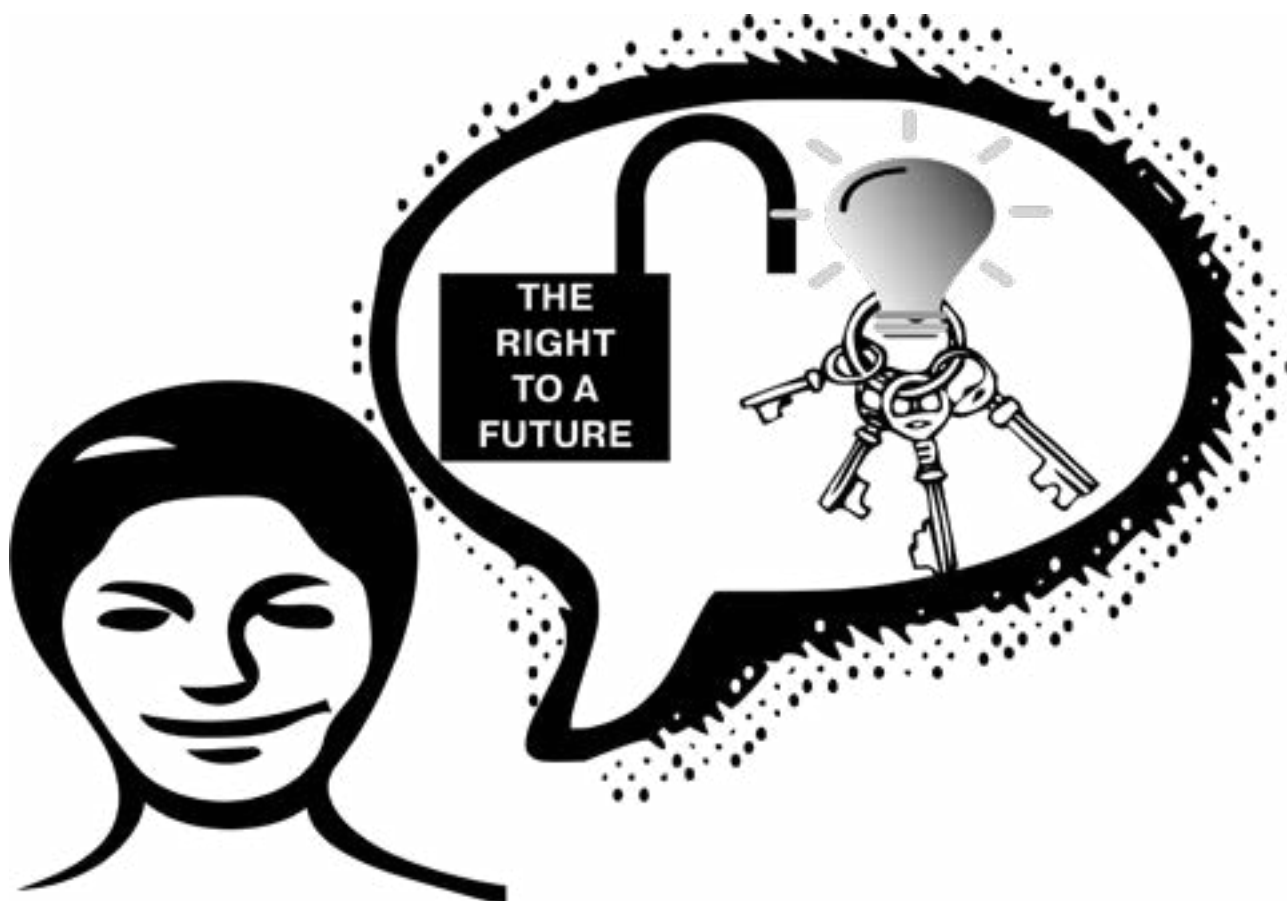
166 Försäkringskassan. Rapport – Analys av minskat antal mottagare av assistansersättning. Stockholm: Försäkringskassan, 2020. <https://www.forsakringskassan.se/download/18.3a5418591814e228e441155/1657122938547/analys-av-minskat-antal-mottagare-av-assistansersattning-svar-pa-regeringsuppdrag-dnr-001381-2020.pdf> (Retrieved 2023-01-03). 22.

167 Socialstyrelsen – Insatser för personer med funktionsnedsättning Lägesrapport 2021. Stockholm: Socialstyrelsen, 2021. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7327.pdf> (Retrieved 2023-01-03). 64.

168 Socialstyrelsen. Registret över insatser enligt lagen om stöd och service till vissa funktionshindrade. Socialstyrelsen. 2018. <https://www.socialstyrelsen.se/statistik-och-data/register/insatser-enligt-lss/> (Retrieved 2023-01-03).

169 SOU 2021:37. Stärkt rätt till personlig assistans – Ökad rättssäkerhet för barn, fler grundläggande behov och tryggare sjukvårdande insatser.

Concluding Reflections and Recommendations



Even if the old, large institutions have disappeared, the goal that disabled persons shall be able to live like others included in the community has still not been achieved. Many live in small institutions, where they often lack opportunities of self-determination and full participation. In this section recommendations to better today's situation are given.

Do Not Forget the Dark History of the Institutional Era and the Past Mistakes – Beware of the Building of New Institutions.

Even if the large institutions are closed, there seems to be a tendency to abandon the intentions of LSS and the CRPD, and develop small institution-like group homes. It is important to examine these tendencies and fight deterioration and practise that lessen opportunities for a self-determined life. The lack of knowledge of history can lead to faulty decisions. Åsa Strahlemo, chair of DHR (The Swedish Mobility Organisation), reminds us in a debate, jointly written with Funktionsrätt Sverige, to not forget:

“Abuse, violations, loneliness, and sorrow. This was life for many disabled persons placed in institutions. Institutional care is a part of a Swedish history which is seldom told. A public apology would recognise the past violations and take a stand for the equal worth of all human beings. A drive for education combined with a new law would be forceful measures that lessen the risk of repeating what happened in the institutions.”¹⁷⁰

Spread Knowledge on Human Rights

The Swedish goal for disability policy, as stated above¹⁷¹, is based on the CRPD, Agenda 2030, the European convention, and Swedish law. In 2017, the Swedish parliament adopted a national goal for disability policy. The national goal is to achieve equality in living conditions and full participation in the community for disabled persons. Swedish policy shall contribute to increased equality and respect the child’s rights.

Sweden has ratified the CRPD.

The UN CRPD-committee has criticised Sweden for several deteriorations in society’s support for disabled persons. There are also areas where Sweden does not satisfy the convention’s demands or has not acted on the CRPD-committee’s recommendations from 2014. When will the CRPD turn into Swedish law?

The CRPD-committee calls for information on the services concerning the content of the CRPD-articles. Sweden’s disability policy is expected to conform to the convention’s articles according to the adopted national goal for disability policy.

Decisionmakers, staff, social players, and the public need knowledge of the CRPD

and rights for disabled persons. They need to know about the meaning of the articles and their importance in daily life. Public and targeted information and knowledge are needed to achieve the goal of the national disability policy. Knowledge is needed on how accessibility and usability in varying social functions and situations affects disabled persons’ living conditions. This is crucial to avoid institutionalisation.

The European Union Strategy for the Rights of Persons with Disabilities 2021–2030

The UN strategy emphasises that many disabled persons – both adults and children – live excluded from the community and without control over their daily lives. This is mainly due to insufficient personal support in the form of, for example, personal assistance and support for families and the lack of housing and mobility/technical aids.

The European Commission calls upon its member states to:

- Implement good practices for deinstitutionalisation within the area of mental health and regarding all disabled persons, including children, to strengthen the transfer from institutional care to support service in the community.
- Promote and ensure funding for accessible and subsidised housing, which must also be available for disabled persons and elderly disabled persons, and address the challenges of homeless disabled persons.

Ensure Access to Necessary Support Services within Current Laws

Today, the granting of support services entailed by laws such as LSS and SoL are done by restrictive assessments. The criteria for

¹⁷⁰ Strahlemo, Åsa och Magnusson, Veronica och Lago, Anders och Wallenius, Elisabeth. När ska staten be om ursäkt för Vipeholm? Expressen. 2021-06-17. <https://www.expressen.se/debatt/nar-ska-staten-be-om--ursakt-for-vipeholm/> (Retrieved 2023-01-03).

¹⁷¹ Proposition 2016/17:188. Nationellt mål och inriktning för funktionshinderspolitiken.

belonging to the third category of LSS' target groups – “considerable difficulties in daily life activities” – are applied too strictly, meaning for example persons who are deaf, blind, or deafblind are not viewed as belonging to the group. Even some persons with neuropsychiatric impairments are excluded from LSS when assessed according to these criteria. Support may then be granted according to SoL but that entails lower quality.

Recurring parliamentary investigations and proposals on how society's costs for support and services for disabled persons can be lowered are worrying. Proposals and implemented changes have worsened the access to personal assistance and the opportunities to live as others. Over 2,000 individuals have lost the right to personal assistance in the form of the national assistance allowance between 2015–2020. Cutbacks on the right to personal assistance result in large difficulties for disabled persons with comprehensive assistance needs as well as families with disabled adults and/or children with comprehensive assistance needs. There is an increased risk of moving from the family into institutional care homes, especially for children and youth.

Persons acquiring impairments after 65 do not have a legal right to personal assistance in the form of the national assistance allowance, but must instead rely on support services from the municipal home care services, where personal assistance is rarely provided. Elderly disabled persons with comprehensive needs risk having to move from their homes to institutional care homes. There is a need

to develop individually adapted support services for the elderly to prevent institutional support services.

According to the Swedish Association of the Local Authorities and the Regions (SALAR), the growth of the number of disabled persons granted housing with special services according to LSS depends on how the situation around personal assistance will develop. If the cutbacks are stopped, and the target group for personal assistance expanded, it is likely that the demand for housing with special services according to the LSS will decline. On the contrary, the need for institutional housing forms increases if fewer persons are granted personal assistance. According to SALAR, municipalities experience uncertainty concerning the future need for housing with special services.¹⁷²

Provide Support to Families with Disabled Children and Youth

Individually adapted support is a prerequisite for disabled children to live with their parents and siblings like other children. Children with one or more impairments have the right to support from society. The Convention on the Rights of the Child (CRC) must be considered. When considering home respite services, the parents' and siblings' situation also need to be taken into account.

From the age of 15 you apply for support services yourself, but in reality parents or guardians must apply for most support services. If the child is younger than 15 years, or clearly unable to apply themselves, the parents or guardian, alternatively a trustee

172 Sveriges Kommuner och Regioner. Stöd för prognos av boende enligt LSS. Stockholm: SKR, 2020. https://skr.se/download/18.4829a209177db4e31aa26f4e/I615197367613/Rapport_%20Prognos_av_boenden_%20enl_%20LSS_%20slutv.pdf (Retrieved 2023-01-03). 48.

or legal guardian, applies for support. The life of the child/youth is affected by many social actors. It can include support services from the children's health centre, pre-school, school, school health care, health and medical services including rehabilitation, support services under SoL and LSS, etcetera. Collaboration and coordination are demanded to facilitate the family and provide the best support possible.

Today's young adults with mild cognitive impairments born after the institutions' closing to a larger extent wish to live in their own flats included in the community. And they want access to real jobs. Dreams about a future with opportunities comparable to others are a result of disabled children and youth living in their families included in pre-school, school, and leisure activities in the community.

Provide Powerful Support Services to Persons with Mental Illness

The World Health Organisation (WHO) defines mental health as a state of well-being in which an individual realises their abilities, can cope with the normal stress of life, can work productively, and contribute to their community.¹⁷³

Mental illness is one of the biggest public health challenges. Researchers foresee that every other Swede of working age will suffer from mental illness sometime during their life. At the same time, many feel that mental illness is a taboo topic, and many do not dare to talk openly about their difficulties and/or diagnosis.¹⁷⁴

Impairments can result in various difficulties and result in exclusion from the community. The situation of persons with neuropsychiatric impairments became a topic of discussion first after the institutional era. Early and individually adapted support services are crucial for a functioning future.

Mental illness is more prevalent among persons with cognitive impairments and autism than among the rest of the population. The National Board of Health and Welfare emphasises the importance of paying attention to mental illness within the LSS target groups.¹⁷⁵

Combat Institution-Like Habits in Current Support Services according to SoL and LSS

Even in service forms produced after the institutional era, there are risks of institution-like methods, habits, and routines lacking respect for the individual's development and becoming a permanent feature of the support. Most housing with services for adults according to LSS follow the guidelines on the number of residents. But 7 percent of all group homes have more than 7 residents, which involves risks for institutional living conditions. For example, leisure activities or activities demanding support from staff are not possible in all group homes after 9 o'clock at night.¹⁷⁶ Respect for the rights entailed by the CRPD must be the foundation of the working methods in group homes. Support in housing with special services is often formed within a framework of formal and informal rules that are institution-like; for example rules on visiting hours and over-

173 World Health Organization. Mental health: strengthening our response. WHO. 2022. <https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response> (Retrieved 2023-01-03).

174 RSMH. Snacka psykisk ohälsa. RSMH. <https://rsmh.se/snacka-psykisk-ohalsa/> (Retrieved 2023-01-03).

175 Socialstyrelsen – Insatser för personer med funktionsnedsättning Lägesrapport 2021. Stockholm: Socialstyrelsen, 2021. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7327.pdf> (Retrieved 2023-01-03). 11.

176 Socialstyrelsen. Insatser och stöd till personer med funktionsnedsättning – Lägesrapport 2020. Stockholm: Socialstyrelsen, 2020. 65.

night stays. Pets are usually not allowed in special housing. Most units also note that they have had difficulties recruiting staff during the last years. There are also challenges concerning staff competency in housing with special services according to LSS. For example, several units observe the need for more knowledge on alternative and complementary communication, and on treatment and attitude. When disabled persons get support from a joint staff group, there is always a risk of formal and informal regulatory frameworks being created, which can limit the individual's self-determination. The Independent Living movement calls these mobile institutions.¹⁷⁷

Act Against Vulnerability and Violence

Violence and abuse against disabled children and adults must be attended to and remedied with knowledge and methods respecting human rights. Incidents must be reported to the police and subject to a criminal investigation.

Notifications to the Health and Social Care Inspectorate (IVO) under Lex Sarah are most

prevalent for personal assistance and housing with special services for adults according to LSS. It is important to address serious wrongdoings within support provision for disabled persons. The most common causes of Lex Sarah notifications according to LSS are poor reception and that the granted support service is inadequately – or not at all – provided.¹⁷⁸

40 years ago, Sweden became the first country in the world to outlaw corporal punishment of children, as well as all forms of violence against children. Violence against children is harmful, unethical, and a violation of their fundamental human rights. In the youth homes of the Swedish National Board of Institutional Care (SIS), children and youth with serious psychosocial problems, or who have been sentenced to secure youth care, are placed. It emerges from the Children's Rights Bureau's report of 2020 on SIS homes that it is the youngest children between 11–12, girls, and disabled children, who are subjected to the largest part of violence. More often than not, it involves children who should have a right to and be granted support services according to LSS.¹⁷⁹

Even if the large institutions are closed, there seems to be a tendency to abandon the intentions of LSS and the CRPD, and develop small institution-like group homes. ”

177 Ratzka, Adolf. Personlig Assistanstjänst: Ett försök till en operationell definition. Independent Living Institute. 1992. <https://www.independentliving.org/toolsforpower/tools15b.html> (Retrieved 2023-01-03).

178 Socialstyrelsen – Insatser för personer med funktionsnedsättning Lägesrapport 2021. Stockholm: Socialstyrelsen, 2021. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7327.pdf> (Retrieved 2023-01-03). 120.

179 Dagens Nyheter, 22/10/2021.

Final Remarks with Summary of the Recommendations

For some individuals, the present time is better than before. For others, dependency is continued where individuals lack control over vital parts of their daily life. The views and values of disabled persons are constantly evolving. The political climate hardens, and decisions are made which limits the daily life of the individual and their opportunity for self-determination and full participation.

We are reminded of how important it is *to not forget the dark history of the institutional era and all the past mistakes*. It is important to spread knowledge on human rights. Decisionmakers, staff, social players, as well as the public must know of the CRPD and the rights of disabled persons. Knowledge of the meaning of the CRPD articles and its significance in everyday life is necessary. Knowledge is needed about how accessibility and usability to various societal functions and situations affect living conditions and the implementation of rights for disabled persons. Ensure access to necessary support services under current laws. Cutbacks within the welfare sector results in reductions in necessary daily support services. Implemented changes have worsened the access to personal assistance and lessened the opportunity to live like others. There is an increased risk of individuals being forced to move away from their family or homes to institutional or communal housing forms. With the knowledge of the effect of the pandemic, it is important to develop individually adapted support services for the elderly to prevent institutional support services. Provide support to families with disabled children and youth. Individual support is a prerequisite

for disabled children to live together with their parents and siblings like other children. The Convention on the Rights of the Child (CRC) must prevail. Support for parents and siblings is important, among other things, home respite services when needed.

Provide powerful support services to persons with mental illness. This is one of our largest public health challenges. Every other Swede of working age will sometime during their life suffer from mental illness. Mental illness is still a taboo topic, and many do not dare to talk openly about their situation. Early and individually adapted support services are crucial for a functioning future. *Combat institution-like habits in current support services within SoL and LSS.* Even in service forms developed after the closing of the large institutions, there is a risk that institution-like methods live on. Habits and routines lacking respect for individual development has become a permanent part of the support. Knowledge of the rights recognised by the CRPD for daily life, competence development in communication, and a dignified treatment is needed. *Act against vulnerability and violence* against both disabled children and adults. The vulnerability of disabled persons must be noted and remedied with knowledge of professional methods that respect human rights.

We hope this publication can contribute to a societal movement in the right direction, where the CRPD becomes more respected and implemented so disabled persons can live equal lives – where they themselves, or with support from others, can make the decisions needed for a self-determined life fully included in the community.

Appendixes

Appendix 1 (table) – Institutions and Schooling

The table Institutions and Schooling summarises important events and dates in schooling that took place in institutions and dates for the deinstitutionalisation process for children and youth.

Period/Year	Reform/Activity/Event
1800s	”Vanförestalter” (institutions for “cripples”) is prevailing.
1809	Allmänna institutet för “blinda och döfstumma” (the Public Institute for “Blind and Deaf and Dumb”) opens and later starts schooling for deaf and deafblind children at the Manilla school.
1825	Braille is developed in France.
1842	The parliament introduces primary public schooling (the “Folkskole”-ordinance was enacted in 1842).
1879	The institute for the blind at Tomtebodavägen, with housing and schooling for children with severe visual impairments, is founded. The school was closed in 1986 and reorganised into the Tomtebodavägen School Resource Centre.
1870s	The start of schools for deaf children.
1879	The opening of Eugeniahemmet (an institution with schooling for children with mobility impairments) for “incurable sick” children.
1882	Compulsory school attendance is enacted for children between 7 and 14. However, it does not apply to all children. 1889 Skolplikt för döva införs.
1891	Norrbackainstitutet in Solna is founded under the name Stockholm’s Institution (“Vanförestalt”) for Relief of the “Deformed and Crippled” (“lytta och vanföra”). Norrbackainstitutet conducts care, rehabilitation, schooling, and vocational training for children and adults with mobility impairments. Norrbackainstitutet formally opened in 1935.
1896	Compulsory school attendance is introduced for blind children.
1922	The start of school classes for children with hearing impairments.
1944	The Act Concerning Education and Care for the “Educable Retarded” is enacted. The start of committal to school homes.
1950	The start of special classes for children with mobility impairment.
1955	The Act Concerning Special Boarding Schools in 1955 was to regulate an improved school situation for “mentally retarded” pupils with no additional impairments. The county councils were to be responsible for providing the “mentally retarded” with schooling and care. Compulsory school attendance covers ages 7 to 21/23 years old.

Period/Year	Reform/Activity/Event
1950s and 1960s	Special boarding school is the predominant service for children and youth with cognitive impairments (approximately 3,000 places at its peak). However, the “severely retarded” pupils with additional impairments are excluded from regular schooling (approximately 6,000 children).
1956	The start of school classes for children with visual impairments in Stockholm and Gothenburg.
1962	The Act concerning compulsory school attendance is revised to include children with mobility impairments. The municipalities are responsible for providing schooling.
1965	The Act concerning pupils’ homes, regulating the county councils’ responsibility to provide pupils dwellings for children and youth with mobility impairments, is enacted. The number of school institutions is starting to decrease.
1967	The start of the national upper secondary school for deaf youth in Örebro.
1968	The Care Act is revised, and the issue of schooling for children and youth with cognitive impairments is moved into the Education Act.
1968	Compulsory school attendance/legal right to schooling for children with cognitive impairments is enacted. The regulation of special schools is moved into the Education Act.
1969	The teaching program for primary school applies to the integration of everyone in ordinary classes.
1970/1971	The start of adult schooling for persons with cognitive impairments as a pilot scheme (primary and training school level).
1970s and 1980s	Special boarding schools and care homes for children are closed. Pupils’ homes gradually replace special boarding schools.
1971	Eugeniahemmet is closed. Disabled children must be admitted to municipal schools.
1979	Norrbackainstitutet is closed and replaced by inclusion in municipal schools.
1981	The parliament recognises Sign Language as the first language for deaf persons.
1984	The start of the national upper secondary school for youth with hearing impairment in Örebro.
1986	The Tomtebodas school is closed and replaced by inclusion in municipal schools.
1988–1996	Municipalisation of the special school. Admission without consent is replaced by on demand attending for special primary school, special upper secondary school, and adult schooling.

Appendix 2 (table) – The Institutional Era and its End

The table The Institutional Era and its End summarises decisive decisions regarding institutions in Sweden. The table denotes the dates of crucial laws and decisions concerning the expansion of institutions and their closing. It has been a long and painful journey from being considered “uneducable” and “crippled”, to being enabled to leave the large institutions and keep your own home in the community.

Period/Year	Reform/Activity/Event
1788	An ordinance gives the parish the right to refuse occupation for “inhysehjon” (lodged paupers) and older and less able to work “tjänstehjon” (living-in lower rural workers).
1847	An ordinance on the legal right to poor relief is enacted.
1866	Opening of the first home for “sinneslöa” (the slow of mind).
Start of the 1900s	Persons with cognitive impairments are considered being uneducable and must be protected against society. And society must be protected against them. The ideology of eugenics is prevailing.
1913	The parliament adopts universal pension insurance.
1915	The law on impediments to marriage is enacted.
1918	The law (1918:422) on poor relief is enacted.
Start of the 1900s	“Vanförestalter” (school institutions for “cripples”) are organised; from the end of the 1800s, school homes were built and annexed to institutions.
1920s and 1930s	The start of “Sinnesslövård” (care of persons with cognitive impairments) with special hospitals and institutions for “the slow of mind” and the mentally ill.
1930s	The housing allowances were introduced in the middle of the 1930s and got its current form in 1997.
1934	The “blind allowance” (later “invalid allowance”) is introduced. Recently known as the disability allowance.
1935	The law on forced sterilisation is introduced and includes, among others, certain disabled persons. The law was abolished in 1975.
1940s	Families with children with cognitive impairments are advised to hand over and forget their child. The advice is, for example, written in “Hemmets Läkarebok” (Doctor’s Advice for the Home) from 1949.
1945	Persons cared for by the “poor relief” get the right to vote.
1948	Child benefit is introduced.

Period/Year	Reform/Activity/Event
1948	“Invalid pension” and sick benefits (later early retirement/sickness benefit and from 2003 sickness/activity benefit) are introduced.
1950	Institutional care is prevailing. A substantial expansion of 40 large institutions with approximately 200 places on average is taking place.
1955	The responsibility of schooling and care of persons with cognitive impairments is transferred to the county councils, but special hospitals and special care homes remain under the government’s responsibility.
1955	Universal sick insurance, income-related sickness benefits and subsidised medical care are introduced.
1956	A law reform establishes that social benefit will replace poor relief.
1960	National supplementary pension is introduced.
1960s and 1970s	The expansion of another 40 institutions takes place to manage the queue to institutional placement. When there were no longer any waiting lists for placement in 1980, there was a total of 180 institutions in Sweden.
1960s	The activities of the Disability Committee of 1965 are proceeding between 1965–1975 and result in various reforms. The concept of “normalisation” is adopted with the goal of “inclusion in the community”. “Vanförestalter” (school institutions for persons with mobility impairments) start closing.
1965	The law concerning pupils’ homes regulates housing and care during compulsory school periods for disabled children. The county councils are given the responsibility to provide homes for children and youth with mobility impairments. The number of school institutions is decreasing. The first national upper secondary school starts.
1960s	The expansion of “Fokushus” (housing with services for persons with mobility impairments) kicks off with a national telethon.
1960	Car allowance is introduced.
1968	The Care Act emphasises the need to plan for deinstitutionalisation. Responsibility for the target group is transferred from the government to the county regions/councils.
1968	Electric wheelchairs become a free-of-charge mobility aid.
1970s	The county councils take over the responsibilities for the five national special hospitals. Units of housing with services are being built in the municipalities. Special transport is introduced.
1974	Parental insurance is introduced.
1982	The Social Care Act includes a paragraph concerning support for disabled persons.

Period/Year	Reform/Activity/Event
1984	A national special transport service is introduced.
1985	The Education Act regulates preschool classes, primary schools, upper secondary schools, special schools, and the Saami school. There are also special public teaching forms organised for those who, due to illness or other reasons, are unable to take part in the schools within the public education system.
1985	Rules on beneficial government building loans are widened to also include group homes with requirements of layout and size to prevent the construction of too large units.
1986	The new Care Act regulates a stop for admission to care homes and special hospitals. The county councils and private actors are expected to plan the closure of 200 existing institutions. However, a final date is not set.
1989	The Disability Committee of 1989 was appointed. It resulted in the LSS reform in 1994.
1993	The responsibility for care under the Care Act (for persons with cognitive impairments) is transferred from the county councils/regions to the municipalities.
1994	The right to personal assistance is introduced when the Act Concerning Support and Service to Certain Persons with Functional Impairments (LSS) comes into force. The national assistance allowance is introduced when the Act Concerning Assistance Allowance (LASS) comes into force. LASS regulates the right to national personal assistance for individuals with basic needs over 20 hours per week.
1994	The Care Act is replaced by the LSS. The target group is widened to include children, youth, and adults belonging to one out of three sub-categories. There are ten support services regulated within the LSS.
1995	The Psychiatric Reform is implemented. Compulsory psychiatric care at so-called mental hospitals are to be closed down.
1997	A specific Act concerning the closure of special hospitals and care homes introduces compulsory closing of institutions before 2000. The only existing special hospital closed immediately in 1997. The closer to 1,000 individuals living in the existing 52 care homes move out to their individual municipalities and into suitable homes, included in the community.
1997 and forward	A specific Act concerning the closure of special hospitals and care homes introduces compulsory closing of institutions before 2000. The only existing special hospital closed immediately in 1997. The closer to 1,000 individuals living in the existing 52 care homes move out to their individual municipalities and into suitable homes, included in the community.

Period/Year	Reform/Activity/Event
1999/2000	Från patient till medborgare” (From Patient to Citizen) – the Swedish disability policy – was adopted and to be implemented in 2000–2010 with the CRPD as a foundation.
2008	The Discrimination Act includes disability as one of its grounds for discrimination.
2009	The UN Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the UN in 2006 and ratified by the Swedish parliament in 2009.
2010	The Education Act with the public school system including preschool classes, primary school, special primary school, special school, Saami school, upper secondary school, special upper secondary school, and municipal adult schooling came into effect. After-school leisure centres are also included in the public school system.
2016/2017	The follow-up of the National Action Plan on Disability results in the adoption of the National Goal and Alignment of Disability Policies in Sweden (Prop. 2016/17:188).

The data in the tables Appendix 1 and Appendix 2 are mainly from:

Persson Bergvall, Inger och Sjöberg, Malena. Åratal – Ur handikapphistorien.

Stockholm: Handikapphistoriska Föreningen. 2012.

Grünewald, Karl. Omsorgsrevolutionen. Tidskriften Intra, 2015.

Grünewald, Karl. Från idiot till medborgare. Stockholm: Gothia Förlag AB. 2009.

Appendix 3 – An Insight into Independent Living

Jamie Bolling

*MA Social Anthropology and Director of Independent Living Institute
January 2022*

Independent Living (IL) started in the US in the 1960s and was then spread to Europe. Today it is a global movement. IL is important for us disabled persons. We spend our lives promoting our rights while many others do not understand what we talk about. With this short publication, I want to provide a glimpse of what defines and shapes Independent Living – that we disabled people want to live like ordinary human beings, with full access to our rights.

Independent Living – a Movement

Independent Living is a movement of disabled persons that started in the US in the 1960s.¹ It is a philosophy with fundamental principles of self-determination, equal opportunities, self-respect, full participation, and empowerment.² Its principles guide the movement's work worldwide. Independent Living emerged from the American civil rights movement, where the leaders recognised that disabled persons' needs should be viewed as rights and that the needs of each individual are unique. Independent Living is based on *cross-disability*, meaning that the movement is for everyone who is disabled, no matter kinds of impairments. To view disability issues from a *social perspective* and as rights,

instead from a *medical perspective*, where disabled persons are categorised according to diagnosis, became an important paradigm shift.

Self-representation is fundamental for Independent Living. The IL movement, tired of being represented by politicians and persons collecting money for charities, demanded that their own voices would be heard and that leaders with experiences of living as disabled persons should represent them. They advocated the right to live according to the IL-movement's principles, meaning a life of self-determination, participation, and the right to social services based on the UN Convention on the Rights of Persons with Disabilities (CRPD) and its article 19.³

The IL-movement promoted these rights long before the CRPD came to be, and we gladly refer to the CRPD mirroring the IL-movement's work, both in principles and text.

“Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation.” This is a quote from Adolf Ratzka, one of the Europeans that brought the concept of Independent Living from the US to Europe and spread the movement.⁴ Adolf moved to Sweden in the 1970s and started to advocate for personal assistance. Polio contracted during his teens caused Adolf paralysis affecting his whole body and, among other things, making him dependent on a ventilator and dependent on personal assistance most hours of the day. Adolf continues his definition by stating that Independent Living means that disabled persons demand the same choice and control as their brothers and sisters, neighbours and friends

1 Barnes, Colin och Oliver, Michael. Disabled People and Social Policy – From Exclusion to Inclusion. Greenwich: Pearson Education Limited, 1998. 83.

2 ENIL. FACT SHEET: Independent Living. 2013. <https://enil.eu/independent-living/> (Retrieved 2023-01-18).

3 General Assembly 2006: 61/106. Convention on the Rights of Persons with Disabilities. https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A_RES_61_106.pdf (Retrieved 2023-01-09).

4 Ratzka, Adolf. What is Independent Living – A Personal Definition. Independent Living Institute. 2003. <https://www.independentliving.org/def.html> (Retrieved 2023-01-03).

have in their daily lives, that is: all the things non-disabled persons take for granted. Adolf emphasises that disabled persons want to grow up in their families, go to the local school, use the same bus as their neighbours, have employment in line with their interests and acquired education, and may want to start a family. In order for all of this to be possible, some are in need of service and support, such as personal assistance.

The Independent Living philosophy views disabled persons themselves as the best experts on their lives and their own needs. They need the space to show the solutions they want, which are necessary to live lives with full participation. They must have control over their lives and be provided opportunities to exercise self-determination and think and speak for themselves like all others in the community.

For persons with cognitive impairments, who might be unable to speak for themselves, the IL movement advocates services with supported decision-making. This is instead of others – such as a trustee, legal guardian, parents, or staff – deciding for the person. The support shall be organised so that the person is supported in searching for and processing information to make their own decisions with the aid of supported decision-making.

Peer counselling, or peer support, are important tools used in the movement to

strengthen each other. The participants in peer support groups gain increased self-confidence and learn about social expectations and strategies to navigate society by supporting each other. It also facilitates the desired result of being self-organised and having the power to advocate political change leading to legal protection for human and civil rights.⁵ Exchanging knowledge between individuals who share the experience of being disabled also contributes to the feeling of social connection.

Adolf ends his definition with:

“We are fundamentally ordinary humans who share the same need to feel included, recognised, and loved. As long as we see our impairments as tragedies, people will feel sorry for us. As long as we are ashamed of who we are, our lives will be seen as useless. As long as we stay silent, we will be told by others what to do.”

The principles of Independent Living were adopted on 3rd September 1990 at a European Network for Independent Living (ENIL) meeting held in Holland.⁶ The IL movement was represented in forming the CRPD and succeeded in influencing the text of article 19 and the general comment number 5.

5 ENIL. Peer Support Training Manual. 2014 <https://enil.eu/wp-content/uploads/2022/12/Peer-Support-Training-Manual-Final.pdf> (Retrieved 2023-01-18).

6 ENIL. FACT SHEET: Independent Living. 2013. <https://enil.eu/independent-living/> (Retrieved 2023-01-18).

A Life with Self-Determination

Below is a description of Independent Living based on the general comment number 5 to article 19 of the CRPD:

“A life with self-determination means that disabled persons are provided all the necessary tools to exercise choice and control in their lives. This entails having the opportunity to make all the small and big decisions concerning their own life. Individual autonomy and self-determination are fundamental for a self-determined life. This includes admittance and access to transport, information, communication, personal assistance, housing, daily routines, habits, decent employment conditions, personal relations, clothes, food, hygiene, health and medical services, religious activities, cultural activities, and sexual and reproductive rights. These activities are connected to the development of a person’s identity: where we live and with whom, what we eat, if we want to take a lie-in or go to bed late at night, be indoors or outdoors, have a tablecloth and candle lights on the table, have pets or listen to music. These are the actions and decisions that make us who we are. A self-determined life is an indispensable part of the individual’s autonomy and freedom and does not necessarily mean living alone. It should also not be interpreted as the ability to perform daily activities unaided. Instead, it should be viewed as the freedom to choose and have control in line with the respect for the inherent value and personal autonomy inscribed in article 3a of the CRPD. Independence as a form of personal autonomy means that a disabled person is not deprived of the oppor-

tunity to choose and control their personal lifestyle and daily activities.”⁷

Attempts are made to “kidnap” the Independent Living terminology and use it with a different meaning than the one of the Independent Living philosophy. Different decision-makers at the UN and in different countries can, for example, talk about “personal assistance” in institutions. Therefore, ENIL found it necessary to define important concepts, including Independent Living, personal assistance, deinstitutionalisation, and community-based services.⁸

The definition provided for Independent Living is:

“The daily demonstration of human rights-based disability policies. Independent Living is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives. This includes the opportunity to make real choices and decisions regarding where, with whom, and how to live. Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent, and allow disabled people flexibility in our daily life. Independent Living requires that the built environment, transport, and information are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that Independent Living is for all disabled persons, regardless of gender, age, and the level of support needs.”

7 Myndigheten för delaktighet. Konventionen om rättigheter för personer med funktionsnedsättning Allmän kommentar nr 5 om ett självständigt liv och att vara inkluderad i samhällsgemenskapen. Stockholm: MFD, 2020. <https://www.mfd.se/contentassets/10cbb4a4f8e34299beb96d965c77e8fb/2020-2-allman-kommentar-5-sjalvstandigt-liv-inkluderad-i-samhallsgemenskapen.pdf> (Retrieved 2023-01-03).

8 ENIL. FACT SHEET: Independent Living. 2013. <https://enil.eu/independent-living/> (Retrieved 2023-01-18).

Important IL- concepts

Below are some concepts of importance for the Independent Living ideology. These describe how persons within the movement see themselves and their movement and how they demand respect and rights.⁹

Antidiscrimination

The movement works against the discrimination of disabled persons and for more personal and political power. Disabled persons as a group are disadvantaged in all societal areas: education, work, income, housing, transport, family life and the social, political and economic life in society. The more help from others you need, the more you are in risk of being subjected to paternalism, overprotection, and discrimination. One of the IL ideology's goals is to have laws and legal practise in all countries that makes discrimination on the ground of disability illegal.

Demedicalisation

One of the reasons disabled persons are discriminated against is that they deviate from what persons think is "normal". The community tends to label individuals who are different as "sick". Sick individuals are not expected to work, are exempted from normal obligations, and are marginalised. As long as they, for example, are seen as sick by the public, there will be little understanding of why they would want to live in ordinary homes and not in institutions. One of IL's goals is to clarify for society and disabled persons the difference between being sick and being a healthy "normal" citizen with impairments who has the same right to a good life as everyone else.

Deinstitutionalisation

According to Independent Living, institutionalisation should be understood from a considerably wider perspective than individuals being designated to live a life inside a certain building. Independent Living means that all humans shall be included in the community, no matter their (dis)abilities. It means that we, in general, are against segregated solutions of various kinds: special pre-schools, special schools, special workshops, special housing arrangements, and special transport. One of the goals of the IL movement is to close special, dehumanising, apartheid solutions and enable participation for everyone in the ordinary community. The opposite of deinstitutionalisation is reinstitutionalisation, which is a regression to institution-like forms of support and service. Therefore, *universal design* is an important concept, which is equal to the pursuit of building and developing of goods and services usable for everyone, no matter their (dis)abilities. However, this does not mean we are against necessary separate solutions until society has developed and reached this goal.

Deprofessionalisation

Disabled persons are often viewed as sick individuals who need to be "cured" or at least rehabilitated. Many believe there is a special need for tender and loving care provided by so called professionals in white coats. The more comprehensive the impairment is, the sicker the individual is considered being, and the more professional education is assumed to be needed in order to "look after" said individual. In this way, society has transferred the control over disabled persons' lives from the individual to professionals. Many be-

9 ENIL. Peer Support Training Manual. 2014 <https://enil.eu/wp-content/uploads/2022/12/Peer-Support-Training-Manual-Final.pdf> (Retrieved 2023-01-18).

lieve a doctor or social worker is best qualified to make decisions on disabled persons' lives. The more power transferred to the one wearing the white coat, the less disabled persons believe in their own strength, and the bigger the risk of insufficient access to rights – especially the right to self-determination.

Self-representation

Disabled persons are themselves the best experts on their needs, preferences, and ambitions on how to live their lives and what they need from society to fulfil their obligations as family members and citizens. Non-disabled persons can only be allies in the struggle for equal rights. Nothing about us without us!

The Independent Living Movement

In the 1960s and 70s, disabled people came together to create change in the US. This should be considered from the standpoint of the political climate of that time, where ethnic minorities had started to demand equal rights. Among the leaders of initiatives in several American cities, Ed Roberts in Berkeley and Judith Heumann in New York gained prominent places nationally and internationally. Both Ed and Judith are strong individuals who, due to impairment (in Judith's case from childhood and Ed from his teens) experienced segregation, oppression, and alienation. Both fought against discrimination¹⁰ and were joined by other disabled persons in Europe and other parts of the world fighting for the same cause.¹¹ They wanted to change the world so disabled chil-

dren and adults would not have to encounter the same obstacles they had faced, such as marginalisation and having been forced to live in institutions or be prevented from attending school. They fought against the community's and the transport system's inaccessibility and the medical model – of being considered sick when they were not and how this view blocked opportunities, as in Judith's case from becoming a teacher. They demanded social services based on their needs.¹² Independent Living works against discrimination and oppression and works for human rights, participation, and for political and personal power where the medical diagnosis is not important. IL's main focus lies on the access to rights based on individual needs.

Adolf Ratzka is, as mentioned before, one of the individuals who has been very important for the dissemination of Independent Living in Europe. Adolf received support from the German government to finance assistance while attending university in the US. There, he finally experienced freedom after five years in an institution, going from a life as a patient where everything in his daily life was decided by the hospital staff (even when he could go to the toilet), to a life with personal assistance and self-determination. In 1973, Adolf came to Sweden to conduct his research at the Royal Institute of Technology (KTH). When the money connected to his research ran out, Adolf was provided support from the home care services – something resulting in once again lost self-determination.¹³

¹⁰ Heumann, Judith med Joiner, Kristen. *Being Heumann*. Beacon Press, 2020.

¹¹ Campbell, Jane och Oliver, Mike. *Disability Politics – Understanding our past, changing our future*. Storbritannien: Routledge, 1996.

¹² Gough, Ritva. *Personlig Assistans – en social bemästringsstrategi*. Göteborg: GIL-förlaget, 1994.

¹³ Ratzka, Adolf. *Independent Living-rörelsen banade vägen*. Independent Living Institute. 2012. <https://www.independentliving.org/docs7/IL-banade-vagen.html> (Retrieved 2023-01-03).

The Founders of Independent Living in Sweden (STIL)

Adolf Ratzka started to advocate for personal assistance after experiencing the freedom and support this form of service provides. He mobilised a group of disabled individuals who were recipients of home care services and/or lived in housing with services. He wrote articles about the international models of services and introduced the concept of personal assistance. He suggested that it should be a national service and the government's responsibility and that it should be paid directly to the assistance user. The group organised itself into an association, The Stockholm Cooperative for Independent Living (STIL), which started in 1984.¹⁴

STIL negotiated a pilot project based on the STIL service model, where the City of Stockholm was to provide personal assistance. The assistance users in the project recruited, trained, negotiated salaries with, decided on working schedules with, and fired assistants if needed. The project was a success and resulted in personal assistance becoming a legal right under the Act (1993:387) Concerning Support and Service for Certain Persons with Functional Impairments (LSS).¹⁵ With personal assistance as a civil right for certain persons with impairments, this law was the first of its kind and became enacted in January 1994.

CIL – IL Organisations Worldwide

Centres for Independent Living (CIL) were established and important to promote self-determination, deinstitutionalisation, and provision and control of services led by disabled persons themselves.¹⁶ CILs were established first in the US,¹⁷ and later in European countries and worldwide.¹⁸ National policy proved important to be developed with the influence of the Independent Living movement, as was the case in Sweden with LSS and the work of STIL. The IL movement with its CILs work against medicalisation, as emphasised in the CRPD.¹⁹ The social model of disability is promoted.²⁰

ENIL – The European Umbrella

Adolf Ratzka and some friends from the Independent Living movement organised a conference on personal assistance in Strasbourg in 1989. At this time, personal assistance was hardly known. The IL movement wanted to equip individuals with the knowledge to help spread the concept of personal assistance and the Independent Living ideology. Lothar Sandfort, a wheelchair user and spokesperson for Die Grünen in the German parliament, mobilised the European green parties to fund the conference. 72 disabled persons from more than 20 countries were present.²¹ It was decided to start the *Europe-*

14 Stiftarna av Independent Living i Sverige. STIL. 2022. <https://www.stil.se/> (Retrieved 2023-01-03).

15 Ratzka, Adolf. Independent Living-rörelsen banade vägen. Independent Living Institute. 2012. <https://www.independentliving.org/docs7/IL-banade-vagen.html> (Retrieved 2023-01-03).

16 Swain, John och French, Sally och Cameron, Colin. *Controversial Issues in a Disabling Society*. Storbritannien: Open University Press, 2003.

17 Power, Andrew och Lord, Janet E. och deFranco, Allison S. *Active Citizenship and Disability*. Cambridge: Cambridge University Press, 2013.

18 Swain, John och French, Sally och Cameron, Colin. *Controversial Issues in a Disabling Society*. Storbritannien: Open University Press, 2003.

19 Crock, Mary och Smith-Khan, Laura och McCallum, Ron och Saul, Ben. *The Legal Protection of Refugees with Disabilities – Forgotten and invisible?* Sydney: Edward Elgar Publishing Limited, 2017.

20 Barnes, Colin. *Theories of disability and the origins of the oppression of disabled people in the western society*. Routledge, 1996.

21 European Network on Independent Living. Landing page. ENIL. 2022. <https://enil.eu/> (Retrieved 2023-01-03).

an Network of Independent Living (ENIL)²², of which Adolf Ratzka became the first chairperson. Since then, ENIL has grown and currently has members in over 40 countries in the EU and the European Council. ENIL's work is project funded and promotes Independent Living in Europe and worldwide. Personal assistance, deinstitutionalisation, freedom of movement, and community-based services are all issues promoted by the Independent Living movement. Disabled refugees and migrants is a new issue that has gained interest and resulted in activities carried out by several CILs within the movement.

In 1998, Time Magazine recognised Adolf's work and called him a European visionary. They described how he came from a hospital stay – where he was treated as a vegetable – directly to the flower-power activism of California, and from there to Sweden.²³

The Independent Living Institute (ILI) in Stockholm

The Independent Living Institute (ILI)²⁴ was founded by Adolf Ratzka and Rolf Bergfors in 1993. The idea was to pursue other projects to promote Independent Living and rights for disabled persons in Sweden as well as other countries. Since its start, ILI is a foundation and has pursued a large number of projects to benefit disabled persons. At the centre of all projects is access to rights

and especially access to self-determination and participation in the community.

Here are some of the projects:

*Assistanskoll*²⁵ is the project that has had most impact. It was started as a project funded by the Swedish Inheritance Fund (2007–2010) but has since then developed and is now almost wholly funded by advertising revenue. Assistanskoll is a website that compare different assistance providers, hold a large database, and runs an online newsletter with all things concerning personal assistance. The website is visited by hundreds of thousands of persons every year, and the newsletter currently has 4,600 subscribers.

*Lagen som verktyg*²⁶ (Law as a Tool) worked for increased access to rights for disabled persons by using the law as a tool to counter negative special treatment and structural discrimination.

*Artikel 19 som verktyg*²⁷ (Article 19 as a Tool) is an expansion of *Lagen som verktyg* and shares the same website and database. Artikel 19 refers to article 19 of the CRPD, which primarily mirrors the thoughts and rights of the IL philosophy. The project aims to hasten the implementation of the CRPD and the general comment number 5.

22 European Network on Independent Living. Landing page. ENIL. 2022. <https://enil.eu/> (Retrieved 2023-01-03).

23 Independent Living Insitute. Landing page. Independent Living Insitute. 2022. <https://www.independentliving.org/> (Retrieved 2023-01-03).

24 Independent Living Insitute. Landing page. Independent Living Insitute. 2022. <https://www.independentliving.org/> (Retrieved 2023-01-03).

25 Assistanskoll. Landing page. Assistanskoll. 2022. <https://assistanskoll.se/> (Retrieved 2023-01-03).

26 Artikel 19 som verktyg. Landing page. Artikel 19 som verktyg. 2022. <https://lagensomverktyg.se/> (Retrieved 2023-01-03).

27 Artikel 19 som verktyg. Landing page. Artikel 19 som verktyg. 2022. <https://lagensomverktyg.se/> (Retrieved 2023-01-03).

*Disabled Refugees Welcome*²⁸ aims to improve the reception of disabled migrants into the Swedish community. The project attracted a lot of interest due to its intersectional approach, proximity to the target group, and method development to achieve mutual integration and access to rights. The project has resulted in several new collaborations and activities concerning integration, migration, and disability.

*Anmälningstjänsten*²⁹ (The Reporting Service) has existed and developed since the late 1990s. The web-based service helps individuals and organisations report discrimination to the Swedish Equality Ombudsman and inaccessibility to the municipal building boards.

*PA-tips*³⁰ (Personal Assistance Tips) gather tips and recommendations made by assistance users directed to other assistance users on how to make your personal assistance work in the best way possible.

*Fashion Freaks*³¹ has had a large international impact with its collection of basic patterns and instructions adapted for wheelchair users.

*Disability Rights Defenders*³² is an international network to exchange legal exper-

tise on the rights of disabled persons. The network aims to generate access to rights with equal opportunity as others, and by mutual sharing of legal knowledge. The ability to use the law as a tool is strengthened. The network currently has 2,300 members from more than 100 countries worldwide.

*TRIPS*³³ (Transport Innovation for Disabled People Needs Satisfaction) is an EU project coordinated by ENIL to produce solutions for accessible transport in Europe. The project is carried out in 7 European cities with local partner organisations. ILI is responsible for the Stockholm working group.

Collaboration with Other Organisations

ILI strongly believes in the strength of joining together with other organisations with the same or similar goals, not least other IL organisations such as ULOBA in Norway³⁴, Threshold in Finland³⁵, and ENIL. ILI works together with other disability rights organisations, for example by writing joint consultation responses and debate articles and cooperating in different projects, both in Sweden and abroad.

28 Disabled Refugees Welcome. Landing page. Disabled Refugees Welcome. 2022. <https://disabledrefugeeswelcome.se/> (Retrieved 2023-01-03).

29 Anmälningstjänsten. Landing page. Anmälningstjänsten. 2022. <https://anmalningstjansten.se/> (Retrieved 2023-01-03).

30 PA-tips. Landing page. PA-tips. 2022. <https://patips.se/> (Retrieved 2023-01-03).

31 Fashion Freaks. Landing page. Fashion Freaks. 2015. <https://fashionfreaks.se/> (Retrieved 2023-01-03).

32 Disability Rights Defenders. Disability Rights Defenders. Independent Living Institute. 2022. <https://www.independentliving.org/drd/> (Retrieved 2023-01-03).

33 TRIPS. Landing page. TRIPS. 2022. <https://trips-project.eu/> (Retrieved 2023-01-03).

34 Uloba. Landing page. Uloba. 2022. <https://www.uloba.no/> (Retrieved 2023-01-03).

35 Kynnys. Threshold Association. Kynnys. 2022. <https://kynnys.fi/en/threshold-association/> (Retrieved 2023-01-03).

Appendix 4 – Principles of Independent Living (ENIL)

While persons with disabilities use the term Independent Living, our goal is to participate equally in our communities – exercising our self-determination.

These principals are to guide the work of ENIL:

1. Independent Living is a process of consciousness raising, empowerment and emancipation. This process enables all disabled persons to achieve equal opportunities, rights and full participation in all aspects of society.

2. Disabled people must be able to control this process individually and collectively. To achieve this goal, we provide peer support and use democratic principles in our work.

3. As equal citizens we must have the same access to the basics of life, including: food, clothing, shelter, health care, assistive devices, personal support services, education, employment, information, communication, transportation and access to the physical and cultural environment, the right to sexuality and the right to marry and have children, and peace.

4. The Independent Living Movement must be a cross disability movement, addressing the needs of all disabled persons. For this to occur, we must rid ourselves of any prejudice we have towards persons with disabilities other than our own and encourage the involvement of disabled women and other underrepresented groups. Disabled children should be enabled by their families and society in general to become independent adults.

5. Disabled people must obtain all the requirements for equalization of opportunities and full participation by defining their own needs, choices, and degree of user control.

6. The Independent Living Movement is opposed to the development and maintenance of systems which promote dependency through institutional responses.

7. Disabled people must involve themselves in research and development, planning and decision making, at all levels, in matters concerning their lives.

These above principles were adopted at the ENIL meeting, "Het Timmerholt", Netherlands August 31–September 3, 1990.

***... our goal is to participate
equally in our communities –
exercising our self-determination...*** ”

Appendix 5 – The Strasbourg Resolution

Source: European Network on Independent Living, ENIL

In April 1989, the first European Independent Living Conference was held at the European Parliament in Strasbourg, France. The meeting's theme was personal assistance. The conference resulted in the founding of the European Network for Independent Living, ENIL. Here, the resolution adopted at the conference.

Preamble

We, disabled people from the Netherlands, UK, Denmark, Italy, Switzerland, Sweden, France, Austria, Finland, Belgium, USA, Hungary, Federal Republic of Germany, and Norway, have come together on April 12–14 1989 at the European Parliament, Strasbourg, France. This conference has focused on personal assistance services as an essential factor of Independent Living, which itself encompasses the whole area of human activities, for example housing, transport, access, education, employment, economic security, and political influence.

We, disabled people, recognizing our unique expertise, derived from our experience, must take the initiative in the planning of policies that directly affect us.

To this end we condemn segregation and institutionalization, which are a direct violation of our human rights, and consider that governments must pass legislation that protects the human rights of disabled people, including equalization of opportunities.

We firmly uphold our basic human right to full and equal participation in society as enshrined in the UN Universal Declaration of Human Rights (extended to include disabled people in 1985) and consider that a key prerequisite to this civil right is through Independent Living and the provision of support such as personal assistance services for those who need them.

The recommendations of the UN World Programme of Action (Paragraph 115) spe-

cifically state that "Member States should encourage the provision of support services to enable disabled people to live as independently as possible in the community and in doing so should ensure that persons with a disability have the opportunity to develop and manage these services for themselves".

Resolution 1 of the 43rd United Nations General Assembly (1988) reaffirms the validity of the World Programme of Action, and Resolution 2 stresses that "special emphasis should be placed on equalization of opportunities". Considering these and similar recommendations from both the European Community and the Council of Europe and to ensure that disabled people within Europe should have parity of equalization of opportunities, we stress that these objectives must be achieved.

In support of the international movement of disabled people in Disabled Peoples' International which has a special commitment to setting up a network of initiatives for Independent Living as part of the implementation of equalization of opportunities, we call on governments and policymakers to enforce the following principles:

1. Access to personal assistance service is a human and civil right. These services shall serve people with all types of disabilities, of all ages, on the basis of functional need irrespective of personal wealth, income or marital and family status.
2. Personal assistance users shall be able to choose from a variety of personal assistance service models which together offer the choice of various degrees of user control. User control, in our view, can be exercised by all persons, regardless of their ability to give legally informed consent.
3. Services shall enable the user to participate in every aspect of life such as home, work, school, leisure and travel, and political life. These services shall enable disabled people to build up a family and fulfill all their responsibilities connected with this.

4. These services must be available long term for anything up to 24 hours a day, 7 days a week, and as a short term, or emergency basis. These services shall include assistance with personal, communicative, household, mobility, and other related services.

5. The funding authority shall ensure that sufficient funds are available to the user for adequate training of the user and the assistant, if deemed necessary by the user.

6. Funding must include assistants' competitive wages and employment benefits, and all legal and union required benefits, plus the administrative costs.

7. Funding shall come from one guaranteed source, and to be paid to the individual wherever he/she chooses. Funding shall not be treated as disposable taxable income and shall not make the user ineligible to other statutory benefits of services.

8. The user should be free to appoint all personal assistants, whoever he/she chooses, including family members.

9. Lack of resources, high costs, substantial or nonexistent services shall not be used as a rationale for placing an individual in an institutionalized setting.

10. There shall be a uniform judicial appeals procedure which works independently of the funders, providers or assessors, and is effected within a reasonable amount of time and enables the claimant to receive legal aid at the expense of the statutory authority.

11. In furtherance of all the above, disabled people and their organizations must be decisively involved at all levels of policy making including planning, implementation and development.

We, disabled people, recognizing our unique expertise, derived from our experience, must take the initiative in the planning of policies that directly affect us. ”

Footnotes

- 1 SFS 1997:724. Lagen om avveckling av specialsjukhus och vårdhem.
- 2 General Assembly 2006: 61/106. Convention on the Rights of Persons with Disabilities. https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A_RES_61_106.pdf (Retrieved 2023-01-09).
- 3 Persson, Margareta. Gamla synsätt spökar än – funktionshinder genom tiderna. Stockholm: Instant Book. 2018. 13
- 4 ENIL. Institutions are NOT Solutions: Learning from the Swedish Experience. YouTube. 2016. https://www.youtube.com/watch?v=aFxYBZ2iXc4&ab_channel=EuropeanNetworkonIndependentLiving-ENIL (Retrieved 2023-01-03).
- 5 Bilagor: Table 1 – Institutioner och skolgång, Table 2 – Institutionsepok och dess avveckling.
- 6 SFS 1993:387. Lag om stöd och service till vissa funktionshindrade.
- 7 General Assembly 2006: 61/106. Convention on the Rights of Persons with Disabilities. https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A_RES_61_106.pdf (Retrieved 2023-01-09).
- 8 United Nations. General comment No.5 on Article 19 – the right to live independently and be included in the community. United Nations. 2017. <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live> (Retrieved 2023-01-03).
- 9 General Assembly 2006: 61/106. Convention on the Rights of Persons with Disabilities. https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A_RES_61_106.pdf (Retrieved 2023-01-09).
- 10 United Nations. General comment No.5 on Article 19 – the right to live independently and be included in the community. United Nations. 2017. <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live> (Retrieved 2023-01-03).
- 11 Ratzka, Adolf. Personlig Assistans: Ett försök till en operationell definition. Independent Living Institute. 1992. <https://www.independentliving.org/toolsforpower/tools15b.html> (Retrieved 2023-01-03).
- 12 Myndigheten för delaktighet. Konventionen om rättigheter för personer med funktionsnedsättning Allmän kommentar nr 5 om ett självständigt liv och att vara inkluderad i samhällsgemenskapen. Stockholm: MFD, 2020. <https://www.mfd.se/contentassets/10cbb4a4f8e34299beb96d965c77e8fb/2020-2-allman-kommentar-5-sjalvstandigt-liv-inkluderad-i-samhallsgemenskapen.pdf> (Retrieved 2023-01-03).
- 13 ENIL. FACT SHEET: Independent Living. 2013. <https://enil.eu/independent-living/> (Retrieved 2023-01-18).
- 14 Grünwald, Karl. Från idiot till medborgare. Stockholm: Gothia Förlag AB. 2009. 15.
- 15 DHR. Levande röster i vår historia. Förlag Brevskolan. 1984. 39.
- 16 Sandén, Staffan och Tideman, Magnus. Detta är inte en politisk fråga. Högskolan i Halmstad: Wigforssinstitutet. 1997. 19.
- 17 Independent Living Institute. Standardregler för att tillförsäkra människor med funktionsnedsättning delaktighet och jämlikhet. Independent Living Institute. 1995. <https://www.independentliving.org/standardrules/STILStandardRegler1.html> (Retrieved 2022-12-28).
- 18 Socialstyrelsen. Socialstyrelsens termbank. Socialstyrelsen. 2022. <https://termbank.socialstyrelsen.se/> (Retrieved 2022-12-28).
- 19 Beckett, Angharad E. och Lawson, Anna. The Social and Human Rights Models of Disability: Towards a Complementarity Thesis. The International Journal of Human Rights. Vol. 25, nr.2, 2020: 348–379.
- 20 Söder, M. Handikappbegreppet: en analys utifrån WHO:s terminologi och svensk debatt, Beredningsgruppen för internationella handikappåret 1981. Stockholm: Socialdepartementet, 1981.
- 21 Berg, Susanne och Linder, Ola. Rätten till ett självbestämt liv i samhällsgemenskapen: en essä om grunderna i Funktionsrättskonventionens artikel 19 och Independent Livingideologin. Artikel 19 som verktyg. 2019. <https://lagensomverktyg.se/2019/essa-artikel-19-och-ideologin/> (Retrieved 2022-12-28).
- 22 Oliver, M. The Individual and Social Models of Disability. Leeds: Centre for Disability Studies, Leeds University, 1990. <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Oliver-in-soc-dis.pdf> (Retrieved 2023-01-13).

- 23 Romero, S. et.al. Vågar mot ömsesidig integration. Stockholm: Disabled Refugees Welcome, Independent living Institute, 2019. <https://disabledrefugeeswelcome.se/2019/07/handbok/> (Retrieved 2023-01-03).
- 24 Beckett, Angharad E. och Lawson, Anna. The Social and Human Rights Models of Disability: Towards a Complementarity Thesis. *The International Journal of Human Rights*. Vol. 25, nr.2, 2020: 348–379.
- 25 Askheim, Ole Petter och Starrin, Bengt. ”Empowerment – ett modeord?”. I *Empowerment i Teori och Praktik*, Askheim Ole Petter och Starrin Bengt, 9–12. Stockholm: Gleerups Utbildning AB, 2007.
- 26 ENIL. The Strasbourg Resolutions. Strasbourg: ENIL, 1989, <https://www.independentliving.org/docs2/enilstrasbourgresolutions.html> (Retrieved 2023-01-04). The text is also in appendix 5 of this publication.
- 27 Independent Living Institute. Landing page. Independent Living Institute. 2022. www.independentliving.org (Retrieved 2023-01-10).
- 28 Ratzka, Adolf. Vad är Independent Living – en personlig definition. Independent Living Institute. 2003. <https://www.independentliving.org/defsv.html> (Retrieved 2022-12-28).
- 29 Berg, Susanne och Bylund, Christine. *Innan levde jag, nu existerar jag*. Stockholm: STIL, 2018. https://www.stil.se/sites/default/files/innan_levde_jag_upplaga_2.pdf (Retrieved 2023-01-03). 4–5.
- 30 Berg, Susanne och Bylund, Christine. *Innan levde jag, nu existerar jag*. Stockholm: STIL, 2018. https://www.stil.se/sites/default/files/innan_levde_jag_upplaga_2.pdf (Retrieved 2023-01-03). 34–39.
- 31 Berg, Susanne och Bylund, Christine. *Innan levde jag, nu existerar jag*. Stockholm: STIL, 2018. https://www.stil.se/sites/default/files/innan_levde_jag_upplaga_2.pdf (Retrieved 2023-01-03). 38.
- 32 Artikel på Assistansskoll skriven av Kenneth Westberg, TEMA – Domar i Förvaltningsdomstolarna.
- 33 Socialstyrelsen. Insatser för personer med funktionsnedsättning Lägesrapport 2021. Stockholm: Socialstyrelsen, 2021. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7327.pdf> (Retrieved 2023-01-03).
- 34 Inspektionen för vård och omsorg. Uppföljning av LSS-boenden Slutredovisning av regeringsuppdrag. Stockholm: IVO, 2021. <https://www.ivo.se/globalassets/dokument/publicerat/rapporter/rapporter-2021/slutredovisning-regeringsuppdrag-s2020-09593-uppfoljning-lss-boenden.pdf> (Retrieved 2023-01-03).
- 35 Inspektionen för vård och omsorg. Lex Maria och lex Sarah. IVO. 2022. <https://www.ivo.se/publicerat-material/statistik/lex-maria-och-lex-sarah/> (Retrieved 2023-01-03). Statistiktabeller för lex Sarah, 2020, Table 4.
- 36 Inspektionen för vård och omsorg. Uppföljning av LSS-boenden Slutredovisning av regeringsuppdrag. Stockholm: IVO, 2021. <https://www.ivo.se/globalassets/dokument/publicerat/rapporter/rapporter-2021/slutredovisning-regeringsuppdrag-s2020-09593-uppfoljning-lss-boenden.pdf> (Retrieved 2023-01-03).
- 37 Myndigheten för delaktighet. Konventionen om rättigheter för personer med funktionsnedsättning Allmän kommentar nr 5 om ett självständigt liv och att vara inkluderad i samhällsgemenskapen. Stockholm: MFD, 2020. <https://www.mfd.se/contentassets/10cbb4a4f8e34299beb96d965c77e8fb/2020-2-allman-kommentar-5-sjalvstandigt-liv-inkluderad-i-samhallsgemenskapen.pdf> (Retrieved 2023-01-03).
- 38 Grünewald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 15.
- 39 Grünewald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 11–12.
- 40 FUB. Grünewalds insatser för personer med utvecklingsstörning. FUB. <https://www.fub.se/om-fub/historik/Grunewalds-insatser-for-personer-med-utvecklingsstorning/> (Retrieved 2022-12-28).
- 41 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikaphistorien. Stockholm: Handikaphistoriska Föreningen. 2012. 12.
- 42 Grünewald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 63–76.
- 43 Grünewald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 101–122.
- 44 Grünewald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 427–444.
- 45 FUB. Historik. FUB. <https://www.fub.se/om-fub/historik/> (Retrieved 2022-12-28).
- 46 Persson, Margareta. *Gamla synsätt spökar än – funktionshinder genom tiderna*. Stockholm: Instant Book. 2018. 121,141.
- 47 Grünewald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009.95.
- 48 Grünewald, Karl och Olsson, Thomas. *Utan talan – historia i bild från omsorgerna om utvecklingsstörda*. Stockholm: Liber AB. 1997. 68–78.
- 49 Persson, Margareta. *Gamla synsätt spökar än – funktionshinder genom tiderna*. Stockholm: Instant Book. 2018. 92–93.
- 50 Grünewald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 123–136.
- 51 Grünewald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB. 2009. 123–136.

- 52 Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. *Läkartidningen*. Nr. 44, 2001.
- 53 Grünewald, Karl. *Från Idiot med medborgare*. Stockholm: Gothia Förlag AB, 2009. 171–190.
- 54 Skolverket. *Grundsärskolan*. Skolverket. <https://www.skolverket.se/undervisning/grundsarskolan> (Retrieved 2022-12-28).
- 55 Göransson, Kerstin och Szönyi, Kristina och Tideman, Magnus. *Utbildning och undervisning i särskolan*. Stockholm: Natur & Kultur Läromedel, 2021.
- 56 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen, 2012. 18–19.
- 57 SPSM. Döv eller nedsatt hörsel. SPSM, 2022. <https://www.spsm.se/funktionsnedsattningar/dov-eller-nedsatt-horsel/> (Retrieved 2022-12-28).
- 58 Persson, Margareta. *Gamla synsätt spökar än – funktionshinder genom tiderna*. Stockholm: Instant Book, 2018. 164.
- 59 SRF. *Skolor och undervisning*. Synskadades Museum, 2016. <https://www.srf.nu/om-oss/museet/synskadades-historia/skolor-och-undervisning/> (Retrieved 2022-12-28).
- 60 DHR. *Levande röster i vår historia*. Förlag Brevskolan, 1984. 39.
- 61 Norrbacka & Eugeniahemmets vänner. *Välkommen till Föreningen Norrbacka & Eugeniahemmets vänners egen hemsida på nätet*. Norrbacka & Eugeniahemmets Vänner. <https://www.norrbacka-eh.se/> (Retrieved 2022-12-28).
- 62 Norrbacka & Eugeniahemmets vänner. *Välkommen till Föreningen Norrbacka & Eugeniahemmets vänners egen hemsida på nätet*. Norrbacka & Eugeniahemmets Vänner. <https://www.norrbacka-eh.se/> (Retrieved 2022-12-28).
- 63 Eriksson, Siw. *Siws liv*. Stockholm: Migra förlag, 2004. 21.
- 64 Lind, Aja. *Lämna honom här: boken om Jonas Jacobsson, världens främste manliga paralympier*. Sigma Förlag, 2021.
- 65 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen, 2012. 18–21.
- 66 SFS 2010:800. Skollag.
- 67 SPSM. *Funktionsnedsättningar*. SPSM, 2022. <https://www.spsm.se/funktionsnedsattningar/> (Retrieved 2022-12-28).
- 68 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen, 2012. 12.
- 69 Grünewald, Karl. *Från idiot till medborgare*. Stockholm: Gothia Förlag AB, 2008. 742.
- 70 Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. *Läkartidningen*. Nr. 44, 2001.
- 71 Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. *Läkartidningen*. Nr. 44, 2001.
- 72 Persson, Margareta. *Gamla synsätt spökar än – funktionshinder genom tiderna*. Stockholm: Instant Book, 2018. 253.
- 73 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen, 2012. 5.
- 74 Ramsemar, Erik. *Handikapprörelsen växer fram*. Brevskolan, 1981. 14–20.
- 75 SDR. *Vårt arbete & handlingsprogram*. Sveriges dövas riksförbund, 2022. <https://sdr.org/vart-arbete/> (Retrieved 2022-12-28).
- 76 HRF. *Om HRF*. Hörselskadades Riksförbund. <https://hrf.se/om-hrf/> (Retrieved 2023-01-15).
- 77 SRF. *Om oss*. Synskadades Riksförbund. <https://www.srf.nu/om-oss/> (Retrieved 2022-12-28).
- 78 DHR. *Levande röster i vår historia*. Förlag Brevskolan, 1984. 20–21.
- 79 DHR. *DHR:s historia*. DHR. <https://dhr.se/om-oss/dhrs-historia/> (Retrieved 2022-12-28).
- 80 RBU. *Om RBU*. RBU. <https://rbu.se/om-rbu/> (Retrieved 2022-12-28).
- 81 Grünewald, Karl. *Omsorgsrevolutionen*. Tidskriften *Intra*, 2015. 25.
- 82 Lind, Judith. *Föräldrainflytande och barnets bästa*, i *Utanförskapets historia*. Engwall Kristina och Larson Stig (red.). Lund: Studentlitteratur, 2012. 106.
- 83 FUB. *Om FUB*. FUB, 2022. <https://www.fub.se/om-fub/> (Retrieved 2022-12-28).
- 84 Ekensteen, Vilhelm. *På folkhemmets bakgård*. Prisma förlag, 1968.
- 85 Ekensteen, Vilhelm. ”På folkhemmets bakgård & Anti-Handikapp”. I *Den oändliga vandringen – Handikapphistorisk Årsbok 1990*. Fingraf, 1990. 103.

- 86 Ransemar, Erik. Handikapprörelsen växer fram. Brevskolan, 1981. 126.
- 87 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 42.
- 88 ILI. Independent Living Institute (ILI). Independent Living Institute. 2022. <https://www.independentliving.org/> (Retrieved 2022-12-28).
- 89 Funktionsrätt Sverige. <https://funktionsratt.se/funktionsratt-ratten-att-fungera-i-samhallet-pa-lika-villkor/manskliga-rattigheter/> (Retrieved 2023-01-04).
- 90 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 13–14.
- 91 Allmänna Arvsfonden. <https://www.arvsfonden.se/om-allman-na-arvsfonden/arv-som-utvecklar-sverige> (Retrieved 2023-01-04).
- 92 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 34–35.
- 93 SFS 1965:136. Elevhem för vissa rörelsehindrade barn m.fl.
- 94 Erika Wermeling <http://erikawermeling.se/stiftelsen-fokus/> (Retrieved 2023-01-04).
- 95 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 28.
- 96 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 29.
- 97 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 29.
- 98 SFS 1967:940. Lag angående omsorger om vissa psykiskt utvecklingsstörda
- 99 Grünewald, Karl. Omsorgsrevolutionen. Tidskriften Intra, 2015. 210.
- 100 SFS 1980:620. Socialtjänstlag.
- 101 SFS 1985:568. Lag om särskilda omsorger om psykiskt utvecklingsstörda m. fl.
- 102 Grünewald, Karl. Omsorgsrevolutionen. Tidskriften Intra, 2015. 210.
- 103 Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. Läkartidningen. Nr. 44, 2001.
- 104 Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. Läkartidningen. Nr. 44, 2001.
- 105 SFS 1997:724. Lag om avveckling av specialistsjukhus och vårdhem.
- 106 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 31.
- 107 Ringsby Jansson, Bibbi. ”Institutionsavveckling och sen? Om boende och vardagsliv i nya former för personer med utvecklingsstörning.” I Handikapp – synsätt principer perspektiv. Tideman Magnus (red.).
- 108 Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. Läkartidningen. Nr. 44, 2001.
- 109 Grünewald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. Läkartidningen. Nr. 44, 2001.
- 110 Nirje, Bengt. Normaliseringsprincipen. Lund: Studentlitteratur AB, 2003.
- 111 Riksdagen SE/RA/323051 Handikapputredningen 1965.
- 112 SFS 1980:620. Socialtjänstlagen.
- 113 SOU 1992:52. 1989 års Handikapputredning. Ett samhälle för alla – Handikapputredningens slutbetänkande.
- 114 SFS 1993:387. Lag om stöd och service till vissa funktionshindrade.
- 115 SFS 1985/86: 107. Omsorgslagen 1968.
- 116 SOSFS 2017:30. Hälso- och sjukvårdslagen.
- 117 SFS 2001:453. Socialtjänstlagen.
- 118 SFS 1993:387. Lag om stöd och service till vissa funktionshindrade.
- 119 Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/s00401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02).
- 120 SFS 1993:387. Lag om stöd och service till vissa funktionshindrade.
- 121 Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/s00401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02). Table 8.

- 122 SFS 1993:387. Lag om Stöd och Service till vissa funktionshindrade.
- 123 Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/soo401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02). Table 5b.
- 124 Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/soo401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02). Table 4.
- 125 Socialstyrelsen. Insatser och stöd till personer med funktionsnedsättning – Lägesrapport 2020. Stockholm: Socialstyrelsen, 2020. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-3-6686.pdf> (Retrieved 2023-01-02). 73–74.
- 126 Ratzka, Adolf. Self-determination for Persons with Extensive Disabilities through Direct Payments for Personal Assistance. Independent living institute. 2017. <https://www.independentliving.org/docs7/Self-determination-direct-payments.html> (Retrieved 2023-01-17).
- 127 Grünwald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. Läkartidningen. Nr. 44, 2001.
- 128 Grünwald, Karl. Från idiot till medborgare. Stockholm: Gothia Förlag AB. 2009. 187.
- 129 Grünwald, Karl. Från idiot till medborgare. Stockholm: Gothia Förlag AB. 2009. 472.
- 130 SFS 2008:342. Lag om utjämning av kostnader för stöd och service till vissa funktionshindrade. Förordning SFS 2008:776.
- 131 Grünwald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. Läkartidningen. Nr. 44, 2001.
- 132 Karlsson, Riitta-Leena; from her work with Deinstitutionalisation in the 1990s.
- 133 Grünwald, Karl. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. Läkartidningen. Nr. 44, 2001.
- 134 Grünwald, Karl. Omsorgsrevolutionen. Tidskriften Intra, 2015. 213
- 135 Karlsson, Riitta-Leena; beskrivning av Per from her work with Deinstitutionalisation in the 1990s
- 136 Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/soo401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02). Table 8.
- 137 Socialstyrelsen – Insatser för personer med funktionsnedsättning Lägesrapport 2021. Stockholm: Socialstyrelsen, 2021. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7327.pdf> (Retrieved 2023-01-03).
- 138 Försäkringskassan. Indikatorer för att följa utvecklingen av assistansersättningen 2021. Stockholm: Försäkringskassan, 2021. https://assistanskoll.se/_up/akoll_pdf/Forsakringskassan-rapport-maj2021.pdf (Retrieved 2023-01-03).
- 139 Myndigheten för delaktighet. Konventionen om rättigheter för personer med funktionsnedsättning Allmän kommentar nr 5 om ett självständigt liv och att vara inkluderad i samhällsgemenskapen. Stockholm: MFD, 2020. <https://www.mfd.se/contentassets/10cbb4a4f8e34299beb96d965c77e8fb/2020-2-allman-kommentar-5-sjalvstandigt-liv-inkluderad-i-samhallsgemenskapen.pdf> (Retrieved 2023-01-03).
- 140 SOSFS 2002:9. Socialstyrelsens föreskrifter och allmänna råd om bostad med särskild service för vuxna enligt 9 § 9 lagen (1993:387) om stöd och service till vissa funktionshindrade.
- 141 Persson Bergvall, Inger och Sjöberg, Malena. Åratal – ur handikapphistorien. Stockholm: Handikapphistoriska Föreningen. 2012. 31.
- 142 Sveriges Kommuner och Regioner. Stöd för prognos av boende enligt LSS. Stockholm: SKR, 2020. https://skr.se/download/18.4829a209177db4e31aa26f4e/1615197367613/Rapport_%20Prognos_av_boenden_%20enl_%20LSS_%20slutv.pdf (Retrieved 2023-01-03). 52.
- 143 Grünwald, Karl. Från idiot till medborgare. Stockholm: Gothia Förlag AB. 2009. 451–470.
- 144 Socialstyrelsen. Personer med funktionsnedsättning – insatser enligt LSS år 2010. Stockholm: Socialstyrelsen, 2011. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/statistik/2011-4-18.pdf> (Retrieved 2023-01-03). Table C.
- 145 Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/soo401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02). Table 8.
- 146 Socialstyrelsen. Insatser och stöd till personer med funktionsnedsättning – Lägesrapport 2020. Stockholm: Socialstyrelsen, 2020. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-3-6686.pdf> (Retrieved 2023-01-02). 32.
- 147 Crock, Mary och Smith-Khan, Laura och McCallum, Ron och Saul, Ben. The Legal Protection of Refugees with Disabilities – Forgotten and invisible? Sydney: Edward Elgar Publishing Limited, 2017. 19–22, 21.

- 148 Ds 2008:23. FN:s konvention om rättigheter för personer med funktionsnedsättning.
- 149 Ds 2008:23. FN:s konvention om rättigheter för personer med funktionsnedsättning. Artikel 19.
- 150 Ds 2008:23. FN:s konvention om rättigheter för personer med funktionsnedsättning. Artikel 4.
- 151 Regeringen CRPD/C/SWE/CO/1 Nummer 2020:2, Kommittén för rättigheter för personer med funktionsnedsättning – Sammanfattande slutsatser och rekommendationer.
- 152 Myndigheten för delaktighet. Konventionen om rättigheter för personer med funktionsnedsättning Allmän kommentar nr 5 om ett självständigt liv och att vara inkluderad i samhällsgemenskapen. Stockholm: MFD, 2020. <https://www.mfd.se/contentassets/10cbb4a4f8e34299beb96d965c77e8fb/2020-2-allman-kommentar-5-sjalvstandigt-liv-inkluderad-i-samhallsgemenskapen.pdf> (Retrieved 2023-01-03).
- 153 Berg, Susanne och Linder, Ola. Rätten till ett självbestämt liv i samhällsgemenskapen: en essä om grunderna i Funktionsrättskonventionens artikel 19 och Independent Livingideologin. Artikel 19 som verktyg. 2019. <https://lagensomverktyg.se/2019/essa-artikel-19-och-ideologin/> (Retrieved 2022-12-28).
- 154 Ds 2008:23. FN:s Konvention om rättigheter för personer med funktionsnedsättning. 126.
- 155 Regeringen. Strategi för systematisk uppföljning av funktionshinderspolitiken under 2021-2031. Stockholm: Regeringen, 2021. <https://www.regeringen.se/4aaadf/contentassets/cf8af503cbbc499894549da09ea685af/strategi-for-systematisk-uppfoljning-av-funktionshinderspolitiken-under-2021-2031.pdf> (Retrieved 2023-01-03).
- 156 Proposition 2016/17: 188. Nationellt mål och inriktning för funktionshinderspolitiken.
- 157 SFS 2017:30. Hälso- och sjukvårdslag. SFS 2010:800. Skollag. SFS 2001:453. Socialtjänstlag. SFS 1993:387. Lag om stöd och service till vissa funktionshindrade.
- 158 Inspektionen för vård och omsorg. IVO. www.ivo.se (Retrieved 2023-01-03).
- 159 General Assembly 2006: 61/106. Convention on the Rights of Persons with Disabilities. https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A_RES_61_106.pdf (Retrieved 2023-01-09).
- 160 Ds 2008:23. FN:s Konvention om rättigheter för personer med funktionsnedsättning.
- 161 Förenta nationerna. Förteckning över problem före inlämning av Sveriges kombinerade andra och tredje periodiska rapporter. Förenta nationerna, 2018. <https://funktionsratt.se/wp-content/uploads/2018/10/FNs-fr%C3%A5gelista-p%C3%A5-svenska.pdf> (Retrieved 2023-01-03).
- 162 Socialstyrelsen – Insatser för personer med funktionsnedsättning Lägesrapport 2021. Stockholm: Socialstyrelsen, 2021. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7327.pdf> (Retrieved 2023-01-03).
- 163 Grünwald, Karl. Omsorgsrevolutionen. Tidskriften Intra, 2015. 13.
- 164 Socialstyrelsen. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020. Stockholm: Socialstyrelsen, 2021. https://www.scb.se/contentassets/3ed5a98b9a8b4848ba571c753a75a258/s00401_kd_2020_kk_210407.pdf (Retrieved 2023-01-02).
- 165 Försäkringskassan. Rapport – Analys av minskat antal mottagare av assistansersättning. Stockholm: Försäkringskassan, 2020. <https://www.forsakringskassan.se/download/18.3a5418591814e228e441155/1657122938547/analys-av-minskat-antal-mottagare-av-assistansersattning-svar-pa-regeringsuppdrag-dnr-001381-2020.pdf> (Retrieved 2023-01-03). 9.
- 166 Försäkringskassan. Rapport – Analys av minskat antal mottagare av assistansersättning. Stockholm: Försäkringskassan, 2020. <https://www.forsakringskassan.se/download/18.3a5418591814e228e441155/1657122938547/analys-av-minskat-antal-mottagare-av-assistansersattning-svar-pa-regeringsuppdrag-dnr-001381-2020.pdf> (Retrieved 2023-01-03). 22.
- 167 Socialstyrelsen – Insatser för personer med funktionsnedsättning Lägesrapport 2021. Stockholm: Socialstyrelsen, 2021. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7327.pdf> (Retrieved 2023-01-03). 64.
- 168 Socialstyrelsen. Registret över insatser enligt lagen om stöd och service till vissa funktionshindrade. Socialstyrelsen. 2018. <https://www.socialstyrelsen.se/statistik-och-data/register/insatser-enligt-lss/> (Retrieved 2023-01-03).
- 169 SOU 2021:37. Stärkt rätt till personlig assistans – Ökad rättssäkerhet för barn, fler grundläggande behov och tryggare sjukvårdande insatser.
- 170 Strahlemo, Åsa och Magnusson, Veronica och Lago, Anders och Wallenius, Elisabeth. När ska staten be om ursäkt för Vipeholm? Expressen. 2021-06-17. <https://www.expressen.se/debatt/nar-ska-staten-be-om-ursakt-for-vipeholm/> (Retrieved 2023-01-03).
- 171 Proposition 2016/17:188. Nationellt mål och inriktning för funktionshinderspolitiken.

- 172 Sveriges Kommuner och Regioner. Stöd för prognos av boende enligt LSS. Stockholm: SKR, 2020. https://skr.se/download/18.4829a209177db4e31aa26f4e/1615197367613/Rapport_%20Prognos_av_boenden_%20enl_%20LSS_%20slutv.pdf (Retrieved 2023-01-03). 48.
- 173 World Health Organization. Mental health: strengthening our response. WHO. 2022. <https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response> (Retrieved 2023-01-03).
- 174 RSMH. Snacka psykisk ohälsa. RSMH. <https://rsmh.se/snacka-psykisk-ohalsa/> (Retrieved 2023-01-03).
- 175 Socialstyrelsen – Insatser för personer med funktionsnedsättning Lägesrapport 2021. Stockholm: Socialstyrelsen, 2021. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7327.pdf> (Retrieved 2023-01-03). 11.
- 176 Socialstyrelsen. Insatser och stöd till personer med funktionsnedsättning – Lägesrapport 2020. Stockholm: Socialstyrelsen, 2020. 65.
- 177 Ratzka, Adolf. Personlig Assistans: Ett försök till en operationell definition. Independent Living Institute. 1992. <https://www.independentliving.org/toolsforpower/tools15b.html> (Retrieved 2023-01-03).
- 178 Socialstyrelsen – Insatser för personer med funktionsnedsättning Lägesrapport 2021. Stockholm: Socialstyrelsen, 2021. <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2021-3-7327.pdf> (Retrieved 2023-01-03). 120.
- 179 Dagens Nyheter, 22/10/2021.

Footnotes in appendixes

- 1 Barnes, Colin och Oliver, Michael. Disabled People and Social Policy – From Exclusion to Inclusion. Greenwich: Pearson Education Limited, 1998. 83.
- 2 ENIL. FACT SHEET: Independent Living. 2013. <https://enil.eu/independent-living/> (Retrieved 2023-01-18).
- 3 General Assembly 2006: 61/106. Convention on the Rights of Persons with Disabilities. https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A_RES_61_106.pdf (Retrieved 2023-01-09).
- 4 Ratzka, Adolf. What is Independent Living – A Personal Definition. Independent Living Institute. 2003. <https://www.independentliving.org/def.html> (Retrieved 2023-01-03).
- 5 ENIL. Peer Support Training Manual. 2014 <https://enil.eu/wp-content/uploads/2022/12/Peer-Support-Training-Manual-Final.pdf> (Retrieved 2023-01-18).
- 6 ENIL. FACT SHEET: Independent Living. 2013. <https://enil.eu/independent-living/> (Retrieved 2023-01-18).
- 7 Myndigheten för delaktighet. Konventionen om rättigheter för personer med funktionsnedsättning Allmän kommentar nr 5 om ett självständigt liv och att vara inkluderad i samhällsgemenskapen. Stockholm: MFD, 2020. <https://www.mfd.se/contentassets/10cbb4a4f8e34299beb96d965c77e8fb/2020-2-allman-kommentar-5-sjalvstandigt-liv-inkluderad-i-samhallsgemenskapen.pdf> (Retrieved 2023-01-03).
- 8 ENIL. FACT SHEET: Independent Living. 2013. <https://enil.eu/independent-living/> (Retrieved 2023-01-18).
- 9 ENIL. Peer Support Training Manual. 2014 <https://enil.eu/wp-content/uploads/2022/12/Peer-Support-Training-Manual-Final.pdf> (Retrieved 2023-01-18).
- 10 Heumann, Judith med Joiner, Kristen. Being Heumann. Beacon Press, 2020.
- 11 Campbell, Jane och Oliver, Mike. Disability Politics – Understanding our past, changing our future. Storbritannien: Routledge, 1996.
- 12 Gough, Ritva. Personlig Assistans – en social bemästringsstrategi. Göteborg: GIL-förlaget, 1994.
- 13 Ratzka, Adolf. Independent Living-rörelsen banade vägen. Independent Living Institute. 2012. <https://www.independentliving.org/docs7/IL-banade-vagen.html> (Retrieved 2023-01-03).
- 14 Stiftarna av Independent Living i Sverige. STIL. 2022. <https://www.stil.se/> (Retrieved 2023-01-03).
- 15 Ratzka, Adolf. Independent Living-rörelsen banade vägen. Independent Living Institute. 2012. <https://www.independentliving.org/docs7/IL-banade-vagen.html> (Retrieved 2023-01-03).
- 16 Swain, John och French, Sally och Cameron, Colin. Controversial Issues in a Disabling Society. Storbritannien: Open University Press, 2003.
- 17 Power, Andrew och Lord, Janet E. och deFranco, Allison S. Active Citizenship and Disability. Cambridge: Cambridge University Press, 2013.
- 18 Swain, John och French, Sally och Cameron, Colin. Controversial Issues in a Disabling Society. Storbritannien: Open University Press, 2003.
- 19 Crock, Mary och Smith-Khan, Laura och McCallum, Ron och Saul, Ben. The Legal Protection of Refugees with Disabilities – Forgotten and invisible? Sydney: Edward Elgar Publishing Limited, 2017.
- 20 Barnes, Colin. Theories of disability and the origins of the oppression of disabled people in the western society. Routledge, 1996.
- 21 European Network on Independent Living. Landing page. ENIL. 2022. <https://enil.eu/> (Retrieved 2023-01-03).
- 22 European Network on Independent Living. Landing page. ENIL. 2022. <https://enil.eu/> (Retrieved 2023-01-03).
- 23 Independent Living Insitute. Landing page. Independent Living Insitute. 2022. <https://www.independentliving.org/> (Retrieved 2023-01-03).
- 24 Independent Living Insitute. Landing page. Independent Living Insitute. 2022. <https://www.independentliving.org/> (Retrieved 2023-01-03).
- 25 Assistanskoll. Landing page. Assistanskoll. 2022. <https://assistanskoll.se/> (Retrieved 2023-01-03).
- 26 Artikel 19 som verktyg. Landing page. Artikel 19 som verktyg. 2022. <https://lagensomverktyg.se/> (Retrieved 2023-01-03).
- 27 Artikel 19 som verktyg. Landing page. Artikel 19 som verktyg. 2022. <https://lagensomverktyg.se/> (Retrieved 2023-01-03).
- 28 Disabled Refugees Welcome. Landing page. Disabled Refugees Welcome. 2022. <https://disabledrefugeeswelcome.se/> (Retrieved 2023-01-03).

- 29 Anmälningstjänsten. Landing page. Anmälningstjänsten. 2022. <https://anmalningstjansten.se/> (Retrieved 2023-01-03).
- 30 PA-tips. Landing page. PA-tips. 2022. <https://patips.se/> (Retrieved 2023-01-03).
- 31 Fashion Freaks. Landing page. Fashion Freaks. 2015. <https://fashionfreaks.se/> (Retrieved 2023-01-03).
- 32 Disability Rights Defenders. Disability Rights Defenders. Independent Living Institute. 2022. <https://www.independentliving.org/drd/> (Retrieved 2023-01-03).
- 33 TRIPS. Landing page. TRIPS. 2022. <https://trips-project.eu/> (Retrieved 2023-01-03).
- 34 Uloba. Landing page. Uloba. 2022. <https://www.uloba.no/> (Retrieved 2023-01-03).
- 35 Kynnys. Threshold Association. Kynnys. 2022. <https://kynnys.fi/en/threshold-association/> (Retrieved 2023-01-03).

Sweden has a dark history of institutionalisation and abuse of persons with disabilities. This is a crime against human rights. In Sweden, big institutions have only been closed for about 20 years. Now, we are facing the risk of re-institutionalisation. This is a worrying development and completely against Swedish commitments to the UN conventions.

In other countries, the Independent Living movement is fighting for deinstitutionalisation, and many of these countries consider Sweden a role model. But is that actually the case?

www.independentliving.org – www.stil.se – www.bidragstiftelsen.se



Supported by:

