Freedom to choose with whom, where and how you want to live

–

Deinstitutionalisation (DI) in Sweden
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Do not forget the dark history of the institutional era and past mistakes – Be wary of the building of new institutions.

Spread knowledge on human rights.

Ensure access to necessary support services under current laws.

Provide support to families with disabled children and youth.

Provide forceful support services to persons with mental illness.

Combat institution-like habits in current support services under SoL and LSS.

Take action against vulnerability and violence.

Final remarks with a summary of the recommendations.
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, not least 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 to do so for many.

The rationale behind the austerity services is, of course, the costs, and particularly the costs of personal assistance. In a recently published book, it is noted in a highly critical tone that the costs of the national assistance allowance are higher than the costs of all the authorities under the Ministry of Justice, i.e. the police, the legal system and the correctional system. Many people seem to think it is too costly to give persons with comprehensive impairments the opportunity to live like others. However, it is obviously not as explicitly voiced. Instead, it is said that, of course, these persons should be allowed to live a life like others, but it has to be achieved with cheaper support services than personal assistance. Which support services this could be, is something people are more reticent to say.

The problem is that many persons with comprehensive impairments need the assistance of others to manage what most 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. 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 have to have 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 on average 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 cost.

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. The other year (2017) I looked closer at this. In many cases, personal assistance has been replaced by – precisely, personal assistance. The municipalities simply have found that there was no other alternative. So they have granted municipal personal assistance but with, on average, fewer hours (about 75 per cent as many hours). In other cases, it could be a case of moving the concerned persons to a group home or replacing the assistance with home care services (maybe 30 hours of home care services instead of 130 hours of assistance). It is evident that these alternatives involve a massive decrease in the living standard for the concerned and a lowering in the opportunities to live as others. How big would the savings be 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 per cent of the costs of the assistance allowance, i.e. the costs would only decrease 10-20 per cent despite the massive lowering of living standards for the concerned persons and their next of kin.

For those with comprehensive impairments who want to live as others, 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, for many individuals, 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. It is, for example, more the rule than the exception that attendant services or contact persons that make it possible for the residents to go out for individual activities are not available.
If Sweden shall fulfill the goals of the UN convention and the national laws, there are strong reasons to grant more individuals personal assistance. With a rollback 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 for 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 tens of 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 assistance. Hopefully, this will be the first step for Sweden to become a role model for disability policy once again.

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

Bengt Westerberg

Minister of Social Affairs 1991-1994 when LSS with personal assistance was enacted.
**Introduction**

It has only been 20 years since we in Sweden realised that life in institutions involves a violation of human rights, and 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 it concerns 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, shall 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 ideal 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 deinstitutionalization. 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

\(^1\) SFS nr: 1997:724 Lagen om avveckling av specialsjukhus och vårdhem
\(^3\) Margareta Persson, Gamla synsätt spökar än – funktionshinder genom tiderna. Instant Book 2018.13
\(^4\) ENIL – Den Europeiska Nätverk för Independent Livings film "Institutions are NOT solutions: Learning from the Swedish Experience".
institutions, hidden and forgotten outside family and society. How was the process connected with decisions and implementation of deinstitutionalization (DI)?

The publication begins with a section with 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 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 annexes to the main text. 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.

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 the large institutions, regulated support services in daily life, and improved living conditions for many persons with comprehensive support needs.

The importance of the UN Convention on the Rights of Persons with Disabilities (CRPD) is emphasised in this publication. According to the convention and its general comment number 5 to article 19, nobody shall live in institutions. 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-

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5 Bilagor: Annex 1 – Institutions and schooling, Annex 2 – The institutional era and its ending
7 Convention on the Rights of Persons with Disabilities (CRPD).
8 2017 General Comment on Article 19: Living Independently and Being Included in the Society CRPD/C/18/1. General comment number 5 in UN:s Library General comment no. 5 (2017) on living independently and being included in the community.
determination and participation in the community are illuminated. The main theme of the publication is deinstitutionalisation, and, therefore, it focuses on the right to live where and with whom you want and 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.

**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 deinstitutionalization, 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 institutions. Institutions are not just a specific type of building but are about 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, 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

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10 2017 General Comment on Article 19: Living Independently and Being Included in the Society CRPD/C/18/1.
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.

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 entail a self-determined life, just as little 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.\textsuperscript{11}

Even if institutions can vary in size, name and organisation, they often share some common characteristics. This can, for example, be that the individual is forced to share staff/assistants with others and that they totally lack or only have a limited influence over who is assisting them. It can be that they are isolated from a self-determined life included in the community, lack control over daily life decisions, or cannot choose whom they will 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 changing 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 type”

\textsuperscript{11} Ratzka, A. 1992 \textit{Personlig Assistans: Ett försök till en operationell definition} Independent Living Institute. Personlig Assistans: Ett försök till en operationell definition | Independent Living Institute
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 the priority over a group home.

The Swedish Agency for Participation (MFD)\textsuperscript{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 \textit{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-determination 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 they live and with whom, what they eat, if they 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, which is generally called independence and is seen as a form of personal autonomy, is, according to the independent living movement, about self-determination and that 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 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 living\textsuperscript{13}) is simply to, on an equal opportunity as others in the community have access to choice, control and freedom, as well as individually adapted support to 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.

\textsuperscript{13} ENIL, 2013 *FACT SHEET: Independent Living* p.4  
https://enil.eu/factsheets/
Current terminology and our view of human beings

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

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 limitations of the ability to participate in the community on equal opportunity. Nowadays, the term impairment, which means impaired physical, mental or cognitive ability and functional variation, 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 impairments 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 impairments, while individuals with normative functional variations have a set of functional abilities that fit in with society's norms.

Since the UN Standard Rules, 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 obstacles. The term disability refers to the relation between the surrounding environment and the individual. A disability is created when a person with impairment cannot

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17 Independent Living, Standardregler för att tillförsäkra människor med funktionsnedsättning delaktighet och jämlikhet.
18 Socialstyrelsen, Socialstyrelsens termbank.
participate in the community 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 handicap 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, but it resulted 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 norm that forms the reason why society is organised in a manner that includes persons with abilities which are part of the norm.

22 Oliver, M. 1990 The Individual and Social Models of Disability, Disability Archives, Centre for Disability Studies: Leeds University. The individual and social models of disability Mike Oliver BA PhD Reader in disability studies Thames Polytechnic Paper pres
and excludes other with **non-normative abilities**. To use terms as 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)\textsuperscript{23} realised by the Independent Living Institute (ILI).

The Swedish term “**funktionsrätt**” (a direct English translation is probably ”ability-rights”, but its content might best be translated as ”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 a politic which shall provide access to the rights. The CRPD is based on a human rights model of disability. In Sweden, the convention is also called ”Funktionsrättkonventionen”.\textsuperscript{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, and then full participation based on equal opportunities with others is possible. It can, for example, deal with school, employment and leisure.

**Intersectionality**, i.e. varying social identities connected to, for example, gender, skin colour, sexual orientation or ability, can come with different challenges in society. With an intersectional perspective, it is possible to find that varying combinations of these identities can lead partly to other challenges. A black woman can be facing other challenges than black individuals in general or women in general. The same can apply to a disabled person who also is female, black or homosexual. With an intersectional perspective, the relation between power

\begin{itemize}
  \item \textsuperscript{23} Romero, S. et.al., *Vägar mot ömresidig integration* (Disabled Refugees Welcome: Independent living Institute 2020). 16
\end{itemize}
and inequality and categories of social identities, such as age, class, abilities, race/ethnicity, gender and sexual orientation, can be illuminated and analysed and 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 you need 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 starting in the 1920s when people wanted to be strong and forceful.\(^{25}\)

**Fundamental principles of Independent Living**

Important principles for the struggle for a life with self-determination and equality were set down through the European Network of Independent Living (ENIL) and the Strasbourg Resolution. They can be found in annexes four and five to this text.\(^{26}\)

Adolf Ratzka is one of the founders of ENIL as well as both Independent Living in Sweden (STIL) and ILI. He has described the fundamental principles of independent living, which can be found on ILI’s webpage.\(^{27}\)

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

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\(^{27}\) ENIL 1989 *The Strasbourg Resolutions* [The Strasbourg Resolutions | Independent Living Institute](https://enil.eu/)

ILI, [www.independentliving.org](http://www.independentliving.org)
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 every-day 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 in 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."

Annexe number three to this text contains a longer description of the independent living movement and the Independent Living Institute (ILI) in Stockholm, responsible for this publication.

**Background**

There are many disabled persons who are living with the threat of cutbacks to 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.

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

“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 will be 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.

Prejudiced court judgments and administrative authorities' legal interpretations have caused cutbacks in support, foremost by the Swedish Social Insurance Administration. The number of individuals who have the right to accompany services and contact persons is visibly fewer. Parents of disabled children and youth have difficulty managing their everyday life and

32 Artikel på Assistanskoll skriven av Kenneth Westberg, TEMA - Domar i Förvaltningsdomstolarna
family. 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 children's homes, called housing with special services for children or
youth under LSS, has decreased by 36 per cent since 2010. However, many municipalities
believe there is an increased future need for special children’s homes since disabled children
and youth with comprehensive needs cannot get satisfactory support at home when the national
assistance allowance is cut off. This will mean that children’s right to grow up in the family 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 dwellings 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, under Lex Sarah, are the highest. Children and adults living in special housing
under LSS are especially vulnerable groups since they often, due to different impairments, do
not have to possibility 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. Physical violence, abuse and
psychological violations from staff are also existing. Support and service of good quality

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33 Socialstyrelsen, Insatser och stöd till personer med funktionsnedsättning
Lägesrapport 2021, ISBN 978-91-7555-562-1, Artikelnummer 2021-3-7327. 64
34 IVO, Uppföljning av LSS-boenden
Slutredovisning av regeringsuppdrag Artikelnr IVO 2021 - 11
35 IVO, Statistik om Lex Maria och Lex Sarah,
Lex Sarah anmälningar inom socialtjänst 2020, Tabell 4.
require competent staff. Unacceptable working methods and institutional habits must be eliminated.

The Health and Social Care Inspectorate (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 in the form of a ban on activities, injunctions 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 societies’ and families’ 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 dwelling 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.

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36 IVO, Uppföljning av LSS-boenden Slutredovisning av regeringsuppdrag Artikelnr IVO 2021 - 11. 4
37 MFD, Konventionen om rättigheter för personer med funktionsnedsättning Sammanfattning av Allmän kommentar nr 5 om ett självständigt liv och att vara inkluderad i samhällsgemenskapen Nummer 2020:11RL
The institutional era in Sweden

The history of disabled persons' living conditions in institutions in Sweden is, according to Karl Grunewald, a story about inhumanity and social exclusion. Karl Grunewald 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, Grunewald 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 experiments, 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

38 Karl Grünwald, Från idiot till medborgare (Gothia Förlag AB 2008). 15
Karl Grunewald 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 *From idiot to citizen, the history of the mentally impaired* (original title in Swedish, “Från idiot till medborgare, de utvecklingsstördas historia”) (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. The founders of the Swedish National Association for People with Intellectual Disability (FUB) appreciated Grunewald: “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.”

The laws mirror society’s view over time on the way to organise support for disabled persons. Under the ordinance of 1788 about the parish’s responsibility for “the poor”, every parish had the right to refuse paupers and servants less 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 poor law. 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.

According to Karl Grunewald, 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.

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40 FUB, *Grunewalds insatser för personer med utvecklingsstörning*
41 Inger Persson Bergvall och Malena Sjöberg, *Åratal ur handikapphistorien* (HandikappHistoriska Föreningen 2012 ). 12
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 official 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 and more started to report on the “care of the mentally retarded”.43

Through his travelling inspections, Karl Grunewald was the person 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 the Swedish National Association for People with Intellectual Disability (FUB) was founded in the 1950s, the living conditions for children with cognitive impairments involved being “hidden or forgotten”. Parents were advised to dispose of, 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, Eugeniahemmet in Stockholm that for almost 100 years, was an institution with schooling for children with mobility impairments. “Incurably sick children” from the whole country should be accepted for schooling and medical care.

42 Karl Grünewald, Från idiot till medborgare (Gothia Förlag AB 2008). Kap 3
43 Karl Grünewald, Från idiot till medborgare (Gothia Förlag AB 2008) Kap 7
44 Karl Grünewald, Från idiot till medborgare (Gothia Förlag AB 2008) Kap 30
45 FUB, Historik
Eugeniahemmet was a closed world in Stockholm with locked gates and high fences where many children spent their entire childhood. Eugeniahemmet was closed in 1971 when the parliament decided that children shall live at home and attend the municipal schools where they lived.\footnote{Margareta Persson, 
*Gamla synsätt spökar än - funktionshinder genom tiderna* (Instant Book 2018). 121+141}

Below is a short description of some institutions that have existed for individuals with different impairments.

*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, but in misguided motherly love, wish to keep them at home for as long as possible, which, of course, means considerable stress not only for the mother but for the rest of the environment.”\footnote{Karl Grünwald, *Från idiot till medborgare* (Gothia Förlag AB 2008). 95}

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 toffee to study what the effect on their teeth would be while not providing 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.\footnote{Karl Grünwald&Thomas Olsson, *Utan talan - historia i bild från omsorgerna om utvecklingsstörda* (Liber AB 1997). 68 - 78}

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 laying 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 hold in their hands 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, a public enquiry about the introduction of compulsory school attendance for children with cognitive impairments was appointed. 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, which also happened to the enquiry of 1920.50

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 did not get either habilitation or education. Approximately 6,000 "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 in total lived in school homes. Every city with a paediatric

49 Margareta Persson, Gamla synsätt spökar än - funktionshinder genom tiderna, (Instant bok 2018). 92 - 93
50 Karl Grünewald, Från Idiot med medborgare (Gothia Förlag AB 2008). Kap 8
51 Karl Grünewald, Från Idiot med medborgare (Gothia Förlag AB 2008). Kap 8
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.\footnote{Karl Grünewald, Läkartidningen nr 44/ 2001  Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad}

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.\footnote{Karl Grünewald, \textit{Från Idiot med medborgare} (Gothia Förlag AB 2008). Kap 12}

12,300 pupils were admitted to the compulsory special school in the school year 2019/2020. It was an increase of ten per cent 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.\footnote{Skolverket, \textit{Grundsärskolan - Skolverket}}

However, attending special school instead of regular schooling has proved to have long-term negative effects on the ability to gain employment despite many individuals both wanting to and being able to hold down a job. Closer to 80 per cent of the pupils leaving special schools are

\footnotesize{\begin{itemize}
\item \footnote{Karl Grünewald, Läkartidningen nr 44/ 2001  Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad}
\item \footnote{Karl Grünewald, \textit{Från Idiot med medborgare} (Gothia Förlag AB 2008). Kap 12}
\item \footnote{Skolverket, \textit{Grundsärskolan - Skolverket}}
\end{itemize}}
outside the labour market. Many go from upper secondary special schools to daily activities under LSS instead of 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 up to the 1970s, they were increasing. 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 the public’s view of education changed. The national government assumed responsibility for the education of blind pupils and

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55 Göransson Szönyi Tideman, *Utbildning och undervisning i särskolan* (Natur & Kultur Läromedel 2021)
57 SPSM, *Döv eller nedsatt hörsel*
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 Tomteboda boarding school.

Braille was taught at Tomteboda, even to pupils who had some sight. The education was high class 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.”

Until the 1940s, it was a given that children with visual impairments should be separated from their parents and attend 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 part of Tomteboda was closed. Today, children with visual impairments are integrated into elementary schools in the municipalities.

**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 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 vanföreanstalter, school institutions for “cripples” started. During the first half of the 1900s,

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59 SRF, [Skolor och undervisning - Synskadades Riksförbund](http://www.synskadades_rf.se)
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 from 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 and then disappeared 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. Norrbacka Institutet 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 “handicapped” children and adults with mobility impairments. All school and boarding activities at Norrbacka ended in 1979. 61

60 DHR, *Levande röster i vår historia*, (Förlag Brevskolan 1984). 39
61 Norrbacka & Eugeniahemets vänner, *Norrbacka & Eugeniahemets Vänner*
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 period. 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 this with 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 and be a nice girl, and you will be good in school. You can show us what you learnt already at Christmas. 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 was a part of the family, and no matter what “handicap” or not, 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

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62 Norrbacka & Eugeniahemmets vänner, Norrbacka & Eugeniahemmets Vänner
63 Inger Persson Bergvall och Malena Sjöberg, Åratal - ur handikapphistorien (HandikappHistoriska Föreningen 2012). 22
64 Aja Lind om Jonas Jacobsson, Lämna honom här (Sigma Förlag 2021) s.11
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. Integration became 1969 a concept within school policy with a new teaching programme for elementary schools, which meant that disabled pupils should attend ordinary school classes and get individual support there.\textsuperscript{65}

According to the present school law, all pupils shall get the teaching and aid they need to attend school with good results.\textsuperscript{66} However, there are still four RH-Riksgymnasier national upper secondary schools for pupils with mobility impairments. Their target group is the youth who need adapted teaching, habilitation and maybe housing with service due to comprehensive mobility impairments.\textsuperscript{67}

\textbf{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 in the institutions.\textsuperscript{68}

The care of so called “sinnesslöa” (probably translates to “mentally retarded”, but 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 “difficult-to-treat”. Stays

\footnotesize{\textsuperscript{65} Inger Persson Bergvall och Malena Sjöberg, \textit{Åratal - ur handikapphistorien} (HandikappHistoriska Föreningen 2012). 18 - 21
\textsuperscript{66} Riksdagen, \textit{Skollag} (2010:800)
\textsuperscript{67} SPSM, \textit{Funktionsnedsettning – Specialpedagogiska skolmyndigheten}
\textsuperscript{68} Inger Persson Bergvall och Malena Sjöberg, \textit{Åratal- ur handikapphistorien} (HandikappHistoriska Föreningen 2012).12}
at these were long-lasting without end dates and meant both incarceration and medical experiments. The length of stay at institutions could vary, but for most, it was life-long.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 and the community. In the 1950s, 40 new institutions with, on average, 200 places were built. In the 1960s and 1970s, approximately 40 more institutions were built. 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 committal 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

69 Karl Grünewald, Från idiot till medborgare (Gothia förlag AB 2008), 742
70 Karl Grünewald, Läkartidningen nr 44 2001 Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad
71 Karl Grünewald, Läkartidningen nr 44 2001 Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad
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, not politically important….”.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 meeting places for persons with experience of living with impairments. However, many organisations developed and came to work for societal change towards increased participation.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 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

72 Margareta Persson, Gamla synsätt spökar än - funktionshinder genom tiderna, (Instant bok 2018). 253
73 Inger Persson Bergvall och Malena Sjöberg, Åratal ur handikapphistorien, (HandikappHistoriska Föreningen 2012). 5
74 Erik Ramsemar, Handikapprörelsens växer fram, (Brevskolan 1981).14 - 20
for the right to and the possibility of using Swedish sign language, which is essential for Deaf person’s participation with equal opportunity in 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, not at least 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 vanföreanstalten in Gothenburg, and after that, local associations at other school institutions for “cripples”. The Stockholm association protested 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 institution. 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

75 SDR, Vårt arbete - Sveriges Dövas Riksförbund
76 HRF, HRF i korthet - Hörselskadades Riksförbund
77 SRF, Om oss - Synskadades Riksförbund
78 DHR, Levande röster i vår historia, (Förlag Brevskolan 1984). 20 - 21
(Delaktighet), Power of Action (Handlingskraft), Freedom of Movement (Rörelsefrihet), and the fight for human rights.

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, habilitation, and education is as important today as it was then.

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 Grunewald, the association became important in the struggle against prejudices and an important source of information for the public and the politicians.

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. Today, the association is called the Swedish National Association for People with Intellectual Disability (FUB) and works for the right to a good life for children, youth and adults with cognitive impairments.

In 1969, Vilhelm Ekensteen founded the action group/association Antihandikapp (anti-handicap). The message of the action group was that: "Handicap is to a large extent a
consequence of deficits in society. Many handicaps can be eliminated. It is done by changing society.\footnote{Vilhelm Ekensteen, På folkhemmets bakgård (Prisma förlag 1968).} 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.\footnote{Vilhelm Ekensteen, ”På folkhemmets bakgård & Anti-Handikapp”, i Den oändliga vandringen - Handikapphistorisk Årskok 1990, (Fingraf 1990). 103} The book was reviewed in the daily newspaper Göteborgs Handels- och Sjöfartstidning, where it was described as a rebellious book by a “handicapped”. ”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?”\footnote{Erik Ransemar, Handikapprörelsen växer fram (Brevskolan 1981). 126}

The thought that the issues should be viewed from a community context instead of care issues also was 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 ”handicap” has later influenced, for example, the work of the UN. Anti-handikapprörelsen (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.\footnote{Inger Persson Bergvall och Malena Sjöberg, Åratal ur handikapphistorien (HandikappHistoriska Föreningen 2012). 42}

The Independent Living movement was established in Sweden in 1984 when STIL, the Founders of Independent Living in Sweden (formerly the Stockholm association of independent living), was founded and contributed to the knowledge of the need for self-determination, among other things, the struggle for a 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 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 sees its mission as being 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 a number of large associations which are not part of the umbrella organisation.

**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 and sick benefits, which were 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 changed its name to 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

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88 ILI, [www.independentliving.org](http://www.independentliving.org)
89 Funktionsrätt Sverige, [Mänskliga rättigheter - Funktionsrätt Sverige](http://www.manskratt.se)
available for persons with other impairments than visual. In 1975, it became the handicap allowance.\textsuperscript{90}

In the 1950s, mobility/technical aids started to be developed. Cars were adapted for persons with mobility impairments, and hearing aids were developed. It became possible to receive grants for different aids. The Permobil, an early model of 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) came 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 dwelling.

When disabled persons moved out of the institutions into their own homes, they needed 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.\textsuperscript{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

\textsuperscript{90} Inger Persson Bergvall och Malena Sjöberg, \textit{Åratal - ur handikapphistorien}, (HandikappHistoriska Föreningen 2012).13 - 14
\textsuperscript{91} Allmänna Arvsfonden, \textit{Arv som utvecklar Sverige - Allmänna arvsfonden
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 adaptions if 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.  

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 habilitation 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, 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.

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 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.

92 Inger Persson Bergvall och Malena Sjöberg, Årtal - ur handikapphistorien, (HandikappHistoriska Föreningen 2012).34 - 35
93 Riksdagen, Lag (1965:136) om elevhem för vissa rörelsehindrade barn m.fl.
providing a housing solution to around 300 individuals. When the collected funds in the Fokus foundation were about to run out, the experiment was finished. 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 being available 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, which demanded accessible dwellings 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, which was their only housing alternative. The survey showed deeply undignified living conditions. More than half of the concerned had to go to bed before seven o’clock at night, and only 40 per cent 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 dwelling with good accessibility and good standard of space

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94 Erika Wermeling Epokgörande tillgänglighet och ifrågasatt välgörenhet – ett stycke historia – Erika Wermeling
95 Inger Persson Bergvall och Malena Sjöberg, Årtal - ur handikapphistorien, (HandikappHistoriska Föreningen 2012). 28
96 Inger Persson Bergvall och Malena Sjöberg, Årtal - ur handikapphistorien, (HandikappHistoriska Föreningen 2012). 29
and equipment in an environment, which provides conditions for active participation in the community.\textsuperscript{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 to gain more influence over their lives, and the municipalities momentarily chose to close housing with services provided by a joint staff group.

\textbf{Laws concerning deinstitutionalisation}

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

\textbf{The care act (1967:940)} was enacted on the 1st of July 1968 to facilitate a planned move out of institutions to 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

\textsuperscript{97} Inger Persson Bergvall och Malena Sjöberg, \textit{Årtal - ur handikapphistorien}, (HandikappHistoriska Föreningen 2012), 29
relief to cope with having their grown up children at home until the county councils had finished building group homes.\textsuperscript{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.\textsuperscript{99}

\textbf{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 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 and organise housing with special services.\textsuperscript{100}

\textbf{The Care Act (1985:568)}\textsuperscript{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 should 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 för 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 of the change, and the number of institutions was approximately 200 when the closing started.\textsuperscript{102}

\textsuperscript{98} Regeringen, Lagen (1967:940) angående omsorger om vissa psykiskt utvecklingsstörda
\textsuperscript{99} Karl Grünwald, \textit{Omsorgsrevolutionen} (Intra 2015). 210
\textsuperscript{100} Riksdagen, Socialtjänstlag- SoL (1980:620)
\textsuperscript{101} Riksdagen, Lagen (1985:568) om psykiskt utvecklingsstörda m.fl.
\textsuperscript{102} Karl Grünwald, \textit{Omsorgsrevolutionen} (Intra 2015). 210
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 meant, in comparison with this, partly that the target group was expanded, so 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, and 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. A compulsory regulation was needed to complement LSS to speed up the process.104 The law dictated that existing special hospitals should immediately close in 1997 and that all residents of institutions should move to suitable forms of dwelling in the community latest in 2000.

All residents of institutions received a decision about their home municipality, which would be responsible for their support. The municipalities should show individual plans for every concerned person to the National Board of Health and Welfare (SoS). The plan should describe the individual’s future dwelling. From the 1st January in 2000, an extension had to be approved

by the SoS if the plan on future dwelling got delayed.¹⁰⁵ Some individuals had lived in
institutions for shorter periods, but many had spent their whole lives institutionalised, in some
cases 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 meeting premises. Personal advisers to
provide support in everyday life were introduced. Despite belonging to the law’s target group,
persons with mental impairments had it hard to receive support under 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 and then outpatient care.

**Closing of institutions**

¹⁰⁵ Riksdagen, Lag (1997:724) om avveckling av specialsjukhus och vårdhem
¹⁰⁶ Inger Persson Bergvall och Malena Sjöberg, Årtal - ur handikapphistorien, Årtal - ur handikapphistorien,
(HandikappHistoriska Föreningen 2012). 31
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 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 in 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 Grunewald, the existence of a political will, that the parliament’s right to legislate trumped local self-determination, and those 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) had 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 disabled persons led to more reforms and the closing of the institutions for individuals with mobility impairments.109

107 Bibbi Ringsby Jansson, Institutionsavveckling och sen? Om boende och vardagsliv i nya former för personer med utvecklingsstörning, i Handikapp - synsätt principer perspektiv, Magnus Tideman (red.), (Johansson & Skyttmo Förlag 1999). 285 - 287
The so called normalisation principle, which involved 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 and 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 like 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

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110 Bengt Nirje, Normaliseringsprincipen (Studentlitteratur AB 2003)
111 Riksdagen SE/RA/323051Handikapputredningen 1965
112 Riksdagen, Socialtjänstlagen (1980:620)
The parliamentary committee on disability of 1989\textsuperscript{113} 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 under LSS. The rights under LSS should be based on the individual’s right to self-determination and meant to provide the necessary support for disabled persons to live in their own homes 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. With housing with services and daily activities, personal assistance became the most sought after support service.\textsuperscript{114}

When LSS was enacted, the main responsibility for the care of persons with cognitive impairments was transferred from the county councils to the municipalities. However, the county councils were still responsible for closing institutions unless they otherwise agreed with the municipality where the institution was located. The medicalised view of disabled persons started to change, and the transfer of responsibility away from the county councils with their responsibility for medical services to the municipalities had 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 habilitation centres, rehabilitation treatment, mobility/technical aids and interpretation were left within the regional administration.\textsuperscript{115}

A change in attitude of disabled persons and their needs was required with disabled persons being 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 dwelling with the support of personal assistance or in a housing unit.

\textsuperscript{113} Regeringen, \textit{1989 års Handikapputredning, Ett samhälle för alla - Handikapputredningens slutbetänkande} (SOU 1992:52)
\textsuperscript{114} Riksdagen, Lag (1993:387) om Stöd och Service till vissa funktionshindrade (LSS)
\textsuperscript{115} Riksdagen, Omsorgslagen 1968 (1985/86:107)
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.

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.

Act concerning trustees and legal guardians (1994:1433)

The act concerning trustees and legal guardians (194:1433) was enacted on the 1st of July 1995 and regulates support to individuals 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 needing to agree. An individual who is
assigned a legal guardian loses the right to conclude agreements or manage their money. This becomes the responsibility of the legal guardian.

**Act concerning future power of attorney (2017:310)**

The Act concerning future power of attorney (2017:310) was enacted on the 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 institutional dwellings. Sweden has three laws that regulate medical services, support and service. 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.

**Health and Medical Services Act, HSL (2017:30)**

The health and medical services act, HSL (2017:30) was enacted on the 1st of 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 have to provide. HSL regulates support services to medically prevent, investigate, and treat sickness and injuries. It regulates rehabilitation, habilitation and access to technical aids. HSL also regulates emergency medical care. Individuals have to be residents in Sweden to have the right to planned medical services.\(^{116}\)

**Social Care Act, SOL (2001:453)**

The Social Care Act, Sol (2001:453) was enacted on the 1st of January 2002 and establishes the main goal of the social welfare services to promote people’s economic and social security,

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\(^{116}\) Riksdagen, Hälsö- och sjukvårdslagen - HSL (2017:30)
equality of living conditions and active participation in the community. Under SoL, the social welfare board in the municipality is responsible for certain groups in society, 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 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 rights in the law can instead apply for support under SoL. It is also possible to receive support under both SoL and LSS simultaneously.117

*Act concerning Support and Services to Certain Persons with Functional Impairments, LSS (1993:387)*

The Act concerning Support and Services to Certain Persons with Functional Impairments (1993:387) was enacted on the 1st of January 1994, and its purpose was to provide disabled persons belonging to its target group with rights to the support needed to be able to live good and self-determined lives unless the needs are satisfied by other means. The support services

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117 Riksdagen, Socialtjänstlagen - SoL (2001:453)
under LSS shall contribute to good living conditions. The right to a good and self-determined life includes, for example, that disabled persons shall have opportunities for their own dwellings, have a family, work, study and/or have a meaningful occupation. Persons with cognitive impairments (belong to the category one or two for the target group - see below) also have the right to daily activities. Individuals will 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, among other things, 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 directly influence the organisation of the support and when it is to be executed. The municipality must consider what is best for the child when providing support services under 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/habilitation, as well as national assistance allowance which is applied for at the Swedish social insurance administration.

**The three categories within LSS’ target group**

LSS does not cover all disabled persons. To be eligible for support services under LSS, an individual has to 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 because a certain diagnosis always results in the individual belonging to the target group of LSS. The assessment of whether an individual belongs to category 3 is based on the person’s difficulties in everyday life.\textsuperscript{118}

Some support services under LSS have certain limitations. Category 3 of the target group 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 under LSS in October 2020. More and more disabled persons receive support services under LSS, and the number has increased by 22 per cent since 2010.\textsuperscript{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 under 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.

\textsuperscript{118} Riksdagen, Lag om stöd och service till vissa funktionshindrade LSS (1993:387).
\textsuperscript{119} Socialstyrelsen, Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020* Art.nr: 2021-4-7321*.
**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.** To have the right to personal assistance, the individual has to need support with so called basic needs. These are 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 relatives and friends. 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, 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, 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 for acute needs.

**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.

**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 LSS. 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 is 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, but the staff is 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. Dwelling in group homes is the most common support measure under § 9 LSS (concerning housing). In October 2020, the

120 Regeringen, Lag (1993:387) om stöd och service till vissa funktionshindrade - LSS
number of adults granted housing with special services was 28,592, and 634 individuals were granted other specially adapted dwellings for adults.\textsuperscript{121}

**Daily activities.** Daily activities are support services for persons of working age belonging to categories 1 and 2, i.e. 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 when many want a “real job” with a salary.\textsuperscript{122}

The table below contains the number of granted support services under LSS between 2010-2020 in the municipalities (rounded values).\textsuperscript{123}

\textsuperscript{121} Socialstyrelsen, Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020 Art.nr: 2021-4-7321. Tabell 8
\textsuperscript{122} Regeringen, Lagen (1993:387) om Stöd och Service till vissa funktionshindrade LSS
\textsuperscript{123} Socialstyrelsen, Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020 Art.nr: 2021-4-7321 Tabell 5b
<table>
<thead>
<tr>
<th>Number of support services under LSS 2010–2020 divided into type</th>
<th>2010</th>
<th>2015</th>
<th>2018</th>
<th>2019</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Advice and other personal support</td>
<td>5,100</td>
<td>4,400</td>
<td>2,100</td>
<td>1,400</td>
<td>900</td>
</tr>
<tr>
<td>2. Personal assistance</td>
<td>3,600</td>
<td>4,300</td>
<td>5,100</td>
<td>5,200</td>
<td>5,400</td>
</tr>
<tr>
<td>3. Accompanying services</td>
<td>9,300</td>
<td>8,300</td>
<td>7,500</td>
<td>7,300</td>
<td>7,000</td>
</tr>
<tr>
<td>4. Contact person</td>
<td>19,500</td>
<td>19,500</td>
<td>19,100</td>
<td>18,700</td>
<td>18,000</td>
</tr>
<tr>
<td>5. In home respite services</td>
<td>3,400</td>
<td>3,800</td>
<td>4,000</td>
<td>4,000</td>
<td>4,000</td>
</tr>
<tr>
<td>6. Short term stays outside the home</td>
<td>10,000</td>
<td>9,700</td>
<td>9,300</td>
<td>9,100</td>
<td>8,800</td>
</tr>
<tr>
<td>7. Short term stays outside the home for pupils over 12 years of age</td>
<td>5,200</td>
<td>4,400</td>
<td>4,500</td>
<td>4,600</td>
<td>4,500</td>
</tr>
<tr>
<td>8 Foster families or housing with special services for children/youth</td>
<td>1,400</td>
<td>1,000</td>
<td>900</td>
<td>900</td>
<td>900</td>
</tr>
<tr>
<td>9. Housing with special services for adults or other specially adapted dwellings</td>
<td>23,400</td>
<td>26,500</td>
<td>28,200</td>
<td>28,700</td>
<td>29,200</td>
</tr>
<tr>
<td>10. Daily activities</td>
<td>30,200</td>
<td>35,300</td>
<td>37,800</td>
<td>38,300</td>
<td>39,000</td>
</tr>
<tr>
<td><strong>Total number of support services</strong></td>
<td><strong>111,100</strong></td>
<td><strong>117,200</strong></td>
<td><strong>118,600</strong></td>
<td><strong>118,100</strong></td>
<td><strong>117,800</strong></td>
</tr>
</tbody>
</table>
On the 1st of October 2020, there were 75,800 persons receiving at least one municipal service measure under LSS. Approximately 89 per cent of these were persons with cognitive impairments, autism or autism-like conditions. The most common service measure was daily activities. 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.

**Laws on housing adaptation and public transport**

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

**Act concerning home adaptation allowance (2018: 222)**

The Act concerning home adaptation allowance regulates allowance to adapt a disabled person’s own dwelling 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 dwellings.

**Act concerning special transport services (1997:736)**

The Act concerning special transport services was enacted on the 1st January 1998 and regulates permits for special transport services for persons with comprehensive difficulties of unaided mobility due to permanent impairment.

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124 Socialstyrelsen, Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020 Art.nr: 2021-4-7321, Tabell 4
**Act concerning national special transport services (1997:735)**

The Act concerning national special transport services was enacted on the 1\textsuperscript{st} 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.

**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 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.


Car allowance can be granted to persons under 65 with permanent impairments and comprehensive mobility difficulties, and 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 the 1\textsuperscript{st} 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 individually organised support in the daily living situation, which can enable a person to move out of a group home and into their own dwelling, as was the case for Maja:

"Before the LSS-reform I lived in a group home. I did not have self-determination, always had to comply with others' wishes and opinions. Now I live in my own home. I want to be able to live like others and decide over my own life. I can only do this if I get to keep my personal assistance (conversation with Maja)."

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.

A full picture of the development within personal assistance requires adding together statistics on the national assistance allowance and personal assistance granted by the municipalities. 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 has to have 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 a pilot project on personal assistance, which was started and carried out by STIL, the founders of independent living in Sweden within the municipality of the city of Stockholm 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 institutional cluster housing/housing with services and the local staff group.

How life before personal assistance was, is described here 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 wide-spread 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.

125 Socialstyrelsen, Lägesrapport 2020 Insatser och stöd till personer med funktionsnedsättning. Artikelnummer 2020-3-6686. 73 - 74
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):

I. “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.

II. 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, i.e., 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.

III. Personal assistance is a one-to-one relationship. Personal assistants must be recruited, trained and supervised by the person granted personal assistance. Personal assistants
IV. 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 responsibilities of "the employer" 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.

How life with assistance can be, 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.”

What was the result? The aftermath of deinstitutionalization?

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 and heavy 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 politicians in decision-making roles who viewed care homes as “without doubt the
organisation which so far proved to "without 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 per cent 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 follow-up, the number of next of kin satisfied was around 80 per cent – i.e. as

126 ILI – Independent Living Institute https://www.independentliving.org/docs7/Self-
determination-direct-payments.html

127 Karl Grünewald, Läkartidningen Nr 44/2001 Avvecklingen av anstaltsvården för
utvecklingsstörda nu fullbordad
many as were negative before the change. Next of kin appreciated that their relative had gotten a better life. Above all, the “personal dwelling, the telephone and the exclusive meeting space that provided possibilities for spontaneous visits and promenades.”

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.”

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.

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128 Karl Grünewald, Från idiot till medborgare (Gothia Förlag AB 2008).187
129 Karl Grünewald, Från idiot till medborgare (Gothia Förlag AB 2008).472
The responsibility for medical services was changed, so the “the care 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 habilitation for children and adults. 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.\textsuperscript{131}

Persons who moved out after living their whole life in an institution could not imagine how, for example, life in their own flat in a group home would work. To furnish and decorate their own home for the first time was a new experience. Next of kin realised that their relatives settled under the new conditions, and life in their own home became calmer and more understandable than in the large institutions. A question for Gustav, 80 years: ”You have furnished your own flat in the group home after a whole life in different institutions. What makes you the most happy in your new home? Gustav: I am most happy to have a door to my home and have my own name on my door 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.”\textsuperscript{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 drugs and fewer hospital visits and slept better at night. Evaluations of individuals with challenging behaviour showed

\textsuperscript{131} Karl Grünewald, \textit{Läkartidningen} Nr 44 2001, \textit{Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad}.
\textsuperscript{132} Riitta-Leena Karlsson, worked with deinstitutionalisation in Stockholm in the 1990s.
improvement for more than half of the group, but a smaller part had the same problems in the group homes.\footnote{133 Karl Grünewald, \textit{Läkartidningen} Nr 44 2001, \textit{Avvecklingen av anstaltsvården för utvecklingstörda nu fullbordad}.}

Persons with challenging behaviour and persons in need of extensive support were moved out of institutions last. 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 more small-scale, calm and understandable. Fewer persons in the small units affected the continuity positively. An evaluation of a number of 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 personality disorders and deviant behaviour had decreased in all and remained less.\footnote{134 Karl Grünewald, \textit{Omsorgsrevolutionen} (Tidskriften Intra 2015). 213}

“\textit{Per was one of the last who moved from a large institution to a group home in the midst of the community of a big city. Per had a challenging behaviour and needed recurrent operation 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.}”\footnote{135 Riitta-Leena Karlssons description of Per from the work with deinstitutionalisation in the 1990s}

\textbf{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 under 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 under 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.  

Families who are not granted personal assistance for their children and cannot manage the situation with available support services have to apply for housing with special services for children and youth under LSS. Children's homes under LSS mean 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 per cent since 2010. However, many municipalities feel there is a future need for the support measure since the assistance allowance has been cut off for children and youth with impairments, complex needs and insufficient support at home.

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.

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136 Socialstyrelsen Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020 Artikelnummer: 2021-4-7321 Tabell 8
137 Socialstyrelsen, Insatser för personer med funktionsnedsättning Lägesrapport 2021 Artikelnummer 2021-3-7327. 64
138 Försäkringskassan, Indikatorer för att följa utvecklingen av assistansersättningen 2021, diarienummer FK 2021/000464. 5
The development is worrying and threatens the possibility of living in an individual dwelling for many.

Group homes with 4-6 dwellings 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 included in the community. The decisive difference between a group home and a self-determined life in your own dwelling is that the first case includes a joint staff group while the other 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 involves enabling a disabled person to participate and become part of the community after living the 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 under LSS have been important for designing new dwellings 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, and the group home to include 4-5 dwellings and a maximum of 6 dwellings. 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.

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139 Myndigheten för delaktighet (MFD), Konventionen om rättigheter för personer med funktionsnedsättning, Allmän kommentar nr 5 om ett självständigt liv och att vara inkluderad i samhällsgemenskapen, Svensk översättning, Nummer 2020:2

140 Socialstyrelsen, Föreskrifter och allmänna råd (SOSFS 2002:9)
    Bostad med särskild service för vuxna enligt 9 § 9 lagen (1993:387) om stöd och service till vissa funktionshindrade, LSS. 4
Group homes have not become 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 having become more independent and able to move to more self-determined housing.

The expansion of group homes and service dwellings continues as they are applied for under 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 dwellings.

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 individuals could meet.\footnote{Inger Persson Bergvall och Malena Sjöberg, Årtal - ur handikapphistorien (HandikappHistoriska Föreningen 2012). 31}

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 under LSS. Belonging to LSS's target group is assessed restrictively, and the municipalities have not used to a large extent the support services under LSS for persons with mental impairments, partly due to the lack of knowledge on the rights under 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 shared corridors and hygiene facilities by many individuals.

The employer organisation The Swedish Association of the Local Authorities and the Regions (SALAR) has said the following: \textit{"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.”

What are the numbers?

LSS regulated the right to housing with special services in the form of group homes or specially adapted dwellings at the same time as the decision to close the institutions was given the definitive final date being 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 under 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 under LSS
In 1997 1,000 individuals remained living in 52 institutions
In 2000 15,800 individuals lived in group homes and service housing under LSS

**Final date for deinstitutionalisation was 1/1/2000**

In 2010 23,400 adults and 1,400 children/youth lived in housing under LSS
In 2020 29,226 adults and 814 children/youth lived in housing under LSS

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142 Sveriges Kommuner och Regioner (SKR), Stöd för prognos av boende enligt LSS, Bostäder enligt Lagen om stöd och service till vissa funktionshindrade (LSS) 2020. 52
143 Karl Grunewald, Från idiot till medborgare (Gothia Förlag AB 2008), Kap 32
144 Socialstyrelsen Personer med funktionsnedsättning – insatser enligt LSS år 2010 Artikelnr 2011-4-18 Tabell C
145 Socialstyrelsen Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020 Artikelnummer: 2021-4-7321 Tabell 8
Over ten years, the costs for support services under LSS have increased by an average of 2.5 percent per year. During the same period, the costs for support services for disabled persons under 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 LSS and SoL in the municipalities has been stable over time; 80 percent of the costs come from LSS while 20 percent come 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 would 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 the 13th of December 2006. Sweden ratified the convention, which came into force in January 2009, and Sweden is, therefore, obligated to implement the rights under the articles of the convention.

**Definitions and principles under the CRPD**

In article 2 of the CRPD, there are several definitions that are important for the convention’s purpose. The definitions below have central importance to understanding the content of the convention’s articles from a Swedish perspective.

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146 Socialstyrelsen, Insatser och stöd till personer med funktionsnedsättning, Lägesrapport 2020. 32
147 Mary Crock, Laura Smith-Khan, Ron McCallum and Ben Saul, *The Legal Protection of Refugees with Disabilities – Forgotten and invisible?* (Edward Elgar Publishing Limited 2017) 19 – 22, 21
**Communication** includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader 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 on the basis of 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,

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 their 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 under the convention. The content in this publication intends to
emphasise crucial aspects of the disability policy from the deficits existing in Sweden today.151

149 OHCHR, Convention on the Rights of Persons with Disabilities
https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-
persons-disabilities Article 3
Regeringen, CRPD Art 19
150 Regeringen, CRPD Art 4
151 Regeringen CRPD/C/SWE/CO/1 Nummer 2020:2, Kommittén för rättigheter för
personer med funktionsnedsättning - Sammanfattande slutsatser och
rekomendationer
**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 under the 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, i.e. a dwelling 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),
- Service is organised in paternalistic ways where someone else decides what is best for the disabled person,
- None or limited influence over who one is, forced to accept assistance (or other services) from,
- Loss of the right to choose where and with whom you live,

\(^{152}\) MFD, Allmän kommentar nr 5 om ett självständigt liv och att vara inkluderad i samhällsgemenskapen MFD Nummer 2020:2
• 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.\textsuperscript{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:

a) 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.

b) 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.

c) Public services and buildings are accessible on equal conditions for disabled persons and are responsive to their needs.\textsuperscript{154}

It is an important task to monitor to what extent communal housing types in Sweden implement and live up to the life qualities under article 19 of the CRPD.

\textbf{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

\textsuperscript{153} Susanne Berg och Ola Linder, \textit{Rätten till ett självbestämt liv i samhällsgemenskapen} (Exellent Print and Design 2020). \textit{Rätten till ett självbestämt liv}

\textsuperscript{154} Sveriges Regering, DS 2008:23 FN:s Konvention om rättigheter för personer med funktionsnedsättning (Edita Sverige AB 2008). 126 \textit{FN:s konvention om rättigheter för personer med funktionsnedsättning}
on a new strategy for systematic monitoring of the national goal 2021-2031.\textsuperscript{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, work has to be focused on four areas:

- The principle of universal design,
- Existing deficiencies in accessibility,
- Individual support and solutions for individual self-determination, and
- Preventing and counteracting discrimination.\textsuperscript{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 and economic and social security and that individuals are given better chances for self-determination.

Laws and monitoring of their implementation 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.\textsuperscript{157}

\textsuperscript{155} Regeringen, Strategi för systematisk uppföljning av funktionshinderspolitiken under 2021–2031 Diarienummer: S2021/06595
\textsuperscript{156} Regeringen, Nationellt mål och inriktning för funktionshinderspolitiken Prop. 2016/17:188
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.\textsuperscript{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.

The Independent Living Institute (ILI) and other disability organisations suspect that the number of individuals living in group homes is increasing, 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?

**Conclusions for the future – What have we learned?**

Even if Sweden formally has closed the large institutions, many disabled persons are in a situation where they lack self-determination in daily life and opportunities to participate in the community are missing. 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 to 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.

\textsuperscript{158} Inspektionen för vård och omsorg (IVO), www.ivo.se
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**

The UN CRPD-committee has criticised Sweden for a number of instances of deterioration in the support services for disabled persons. There are several areas where Sweden lacks implementing rights for disabled persons.

Also, Sweden has not acted on the recommendations the CRPD-committee delivered 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 all of the articles of the CRPD. They deal with, for example, 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.

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Living independently and being included in the community (article 19).

The committee has called 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 qualify personal help. 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, has also been requested. 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 if, and in that case so, to what extent austerity measure has affected this right.  

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 under 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.

There is a lack of knowledge on the background of and work with the closing of the large institutions (which causes opinions to 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). Among many of today’s political decision-makers there is a lack of knowledge

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Förenta nationerna CRPD / C / SWE / QPR / 2-3 Konventionen om rättigheter för personer med funktionshinder Distr. : General 1

162 Socialstyrelsen, Insatser och stöd till personer med funktionsnedsättning Lägesrapport (2021) Statistik om stöd och service till personer med funktionsnedsättning - Socialstyrelsen
on the history and the reasons behind the closure of the large institutions being the poor living conditions and prevalence of violence and abuse in the institutions.

This was illuminated in Karl Grunewald’s historical description in the following way:

“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.”

In budgetary discussions, proposals for cutbacks are constantly recurring. Several support services under 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 not having their individual needs assessed, being considered not having the right to a contact person or accompanying services. The number of individuals granted these services under LSS has decreased by 51 and 61 percent. Persons with visual impairments or who are deaf-blind have, for example, more difficulties getting access to accompanying services under LSS.

The number of recipients of the national assistance allowance has decreased since 2015, by 2,000 individuals, from a little over 16,000 individuals in 2014 to a little more than 14,000 individuals in 2019. A little less than half of the decrease 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 decreased by over 70 per cent. Changes in law and legal precedents have affected the number of individuals with assistance allowance. Changes have meant that fewer individuals are 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

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163 Karl Grunewald, Omsorgsrevolutionen (Tidskriften Intra 2015). 13
164 Socialstyrelsen LSS – statistik. Statistik om insatser enligt lagen om stöd och service till vissa funktionshindrade 2020 Artikelnr: 2021-4-732. 3
more than 300 in 2019.\textsuperscript{165} Alongside legal governance, indirect governance of activities can also exist through documents not formally claimed as regulating.\textsuperscript{166}

Decreasing national personal assistance has increased municipal personal assistance under LSS from 3,550 persons in 2010 to over 5,200 in 2019.\textsuperscript{167} In total, 5,379 individuals had municipal personal assistance under LSS in October 2020.\textsuperscript{168}

Since implementing the LSS-reform, several investigations have involved changes in the right to personal assistance.\textsuperscript{169} Decreasing opportunities for personal assistance increases the risk of re-institutionalisation.

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 is still not 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.

\textsuperscript{165} Försäkringskassan, Rapport – Analys av minskat antal mottagare av assistansersättning Försäkringskassan, s. 9
\textsuperscript{166} Försäkringskassan, Rapport – Analys av minskat antal mottagare av assistansersättning Försäkringskassan, s. 22
\textsuperscript{167} Socialstyrelsen, Insatser och stöd till personer med funktionsnedsättning Lägesrapport 2021 Artikelnummer 2021-3-7327. 64
\textsuperscript{168} Socialstyrelsen, Registret över insatser enligt lagen om stöd och service till vissa funktionshindrade, publicerad i SCB
\textsuperscript{169} Regeringen, Stärkt rätt till personlig assistans – Ökad rättssäkerhet för barn, fler grundläggande behov och tryggare sjukvårdande insatser SOU 2021:37
**Do not forget the dark history of the institutional era and past mistakes – Be wary 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 article, 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 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. An education drive combined with a new law would be forceful measures that lessen the risk of repeating what happened in the institutions.”

**Spread knowledge on human rights**

The Swedish goal for disability policy as stated above 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 a number of deteriorations in society’s support for disabled persons. There are also areas where

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170 Expressen, Debatt: När ska staten be om ursäkt för Vipeholm? Publicerad 18 juni 2021
171 Regeringen, Nationellt mål och inriktning för funktionshinderspolitiken. (Reg.prop. 2016/17:188)
Sweden does not satisfy the convention’s demands or has acted on the CRPD – committee-recommendations from 2014. Will the CRPD become Swedish law? The implementation of rights for disabled persons has deficiencies.

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 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 knowledge about the articles’ meaning and 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 affect disabled persons’ living conditions. This is crucial to avoid institutionalisation.

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

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 is also available for disabled persons and elderly disabled persons and address the challenges of homeless disabled persons.
Ensure access to necessary support services under current laws

Today, the granting of support services under laws such as LSS’ and SoL are done by restrictive assessments. The criteria for belonging to the category three of LSS’ target group – “considerable difficulties in daily life activities” – are applied very narrowly, which means that, for example, persons who are deaf, blind or deaf-blind are not viewed as belonging to the group. Even some persons with neuro-psychiatric impairments are excluded from LSS when assessed according to these criteria. Maybe support is then granted under SoL but with 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 and December 2020. Cutbacks on the right to personal assistance result in large difficulties for disabled persons with comprehensive assistance needs and families with both disabled adults and 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 have to 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 under LSS
depends on how 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 under 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 around 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) and the child perspective must be considered. The parents' and siblings' situation also needs attention when support, for example, in home respite services can be important.

Youth 15 years and older apply for support services themselves, but 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, or legal guardian, applies for support. The life of the child/youth is affected by many social players. It can include support services from the children's health centre, pre-school, school, school health care, health and medical services including habilitation, support services under SoL and LSS, etcetera. Collaboration and coordination are demanded to facilitate the family and provide the best support possible.

172 Sveriges Kommuner och Regioner (SKR), Stöd för prognos av boende enligt LSS, maj 2020. 48
Today's young adults with mild cognitive impairments born after the institutions' closing wish to a larger extent 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.

**Provide forceful 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 taboo, and many do not dare to talk openly about their diagnosis or difficulties.\(^{174}\)

Impairments can result in various difficulties and have persons excluded from the community. The situation of persons with neuro-psychiatric impairments came to the attention of society after the institutional era. Crucial for a functioning future are early and individually adapted support services both during childhood and youth and later when adults.

Mental illness is more prevalent among persons with cognitive impairments and autism than the rest of the population. The National Board of Health and Welfare emphasises the importance

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\(^{173}\) WHO [Mental health: strengthening our response](https://www.who.int/news-room/fact-sheets/detail/mental-health)

\(^{174}\) RSMH, [Snacka psykisk ohälsa - rsmh](https://www.ssmh.se/sodra/sns/snacka_psykisk_ohalsa)
of paying attention to mental illness within the LSS area, for example, during the development of activities and competence.\textsuperscript{175}

\textit{Combat institution-like habits in current support services under 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 under LSS follow the guidelines on the number of residents. But seven per cent of group homes have more than seven residents, which involves risks for institutional living conditions. Leisure activities or activities demanding support from staff are, for example, not possible in all group homes after nine o’clock at night.\textsuperscript{176} Respect for the rights under the CRPD must form the working methods. 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 overnight 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 under 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 the risk that formal and informal regulatory frameworks are created, which can limit the individual’s self-determination. The Independent Living movement calls these mobile institutions.\textsuperscript{177}

\textsuperscript{175} Socialstyrelsen, Insatser och stöd till personer med funktionsnedsättning Lägesrapport 2021 Artikelnummer 2021-3-7327. 11
\textsuperscript{176} Socialstyrelsen, Insatser och stöd till personer med funktionsnedsättning Lägesrapport 2020 Artikelnummer 2020-3-6686. 65
\textsuperscript{177} Ratzka, A. 1992 \textit{Personlig Assistans: Ett försök till en operationell definition} Independent Living Institute \textit{Personlig Assistans: Ett försök till en operationell definition} | Independent Living Institute
Take action 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 under LSS. It is important to address serious wrongdoings within support provision for disabled persons. The most common causes behind Lex Sarah notifications under LSS are poor reception and that the granted support service is inadequately or not at all provided.¹⁷⁸

Forty years ago, Sweden became the first country in the world to outlaw corporal punishment of children and 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 psycho-social 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 the violence. As a rule, it involves children who should have a right to and be granted support services under LSS.¹⁷⁹

¹⁷⁸ Socialstyrelsen, Insatser och stöd till personer med funktionsnedsättning Lägesrapport 2021 Artikelnummer 2021-3-7327. 120
¹⁷⁹ Dagens Nyheter, 22/10/2021
Final remarks with a 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 not to 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 and the public need knowledge about the CRPD and the rights of disabled persons. Knowledge about the meaning of the CRPD articles and its significance in everyday life. 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 result 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 about 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) and the child perspective must prevail. Support for parents and siblings is important, among other things, home respite services when needed. Provide forceful 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 taboo, and many do not dare to talk openly about their situation. Early and individually adapted support services during childhood, during the youth and in adulthood are crucial for a functioning future. Combat institution-like habits in current
support services under Sol and LSS. Even in service forms developed after the closing of the large institutions, there are risks that institution-like methods live on. Habits and routines lacking respect for individual development become a permanent part of the support. Knowledge of the rights under the CRPD for daily life, competence development in communication and a dignified treatment is needed. Take action 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.
Annex 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 deinstitutionalization process for children and youth.

<table>
<thead>
<tr>
<th>Period/Year</th>
<th>Reform/Activity/Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1800s</td>
<td>“Vanföreanstalter” (institutions for “cripples”) is prevailing.</td>
</tr>
<tr>
<td>1809</td>
<td>Allmänna institutet för “blinda och döfstumma” (the public institute for “blind and deaf and dumb”) is founded and later starts schooling for deaf and deaf-blind children at the Manilla school.</td>
</tr>
<tr>
<td>1825</td>
<td>Braille is developed in France.</td>
</tr>
<tr>
<td>1842</td>
<td>The parliament introduces primary public schooling (the ”Folkskole”-ordinance was enacted in 1842).</td>
</tr>
<tr>
<td>1879</td>
<td>The institute for the blind at Tomteboda is housing with schooling for children with severe visual impairments. The school was closed in 1986 and reorganised into the Tomteboda school resource centre.</td>
</tr>
<tr>
<td>1870s</td>
<td>The start of schools for deaf children.</td>
</tr>
<tr>
<td>1879</td>
<td>The start of Eugeniahemmet (school institutions for children with mobility impairments) for “incurable sick” children.</td>
</tr>
<tr>
<td>1882</td>
<td>Compulsory school attendance is enacted for children between 7 and 14. However, it does not apply to all children.</td>
</tr>
<tr>
<td>1889</td>
<td>Compulsory school attendance is introduced for deaf children.</td>
</tr>
<tr>
<td>Year</td>
<td>Event</td>
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<tr>
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</tr>
<tr>
<td>1891</td>
<td>Norrbackainstitutet in Solna is founded under the name Stockholm’s institution (&quot;Vanföreanstalt&quot;) for relief of the “deformed and crippled” (&quot;lytta och vanföra&quot;). Norrbackainstitutet conducts care, rehabilitation, schooling and vocational training for children and adults with mobility impairments. Norrbackainstitutet formally opened in 1935.</td>
</tr>
<tr>
<td>1896</td>
<td>Compulsory school attendance is introduced for blind children.</td>
</tr>
<tr>
<td>1922</td>
<td>The start of school classes for children with hearing impairments.</td>
</tr>
<tr>
<td>1944</td>
<td>The Act concerning education and care for the &quot;educable retarded&quot; is enacted, The start of committal to school homes.</td>
</tr>
<tr>
<td>1950</td>
<td>The start of RH classes for children with mobility impairment.</td>
</tr>
<tr>
<td>1955</td>
<td>The Act concerning special boarding schools in 1955 was to regulate an improved school situation for &quot;mentally retarded&quot; pupils with no additional impairments. The county councils were to be responsible for providing the &quot;mentally retarded&quot; with schooling and care. Compulsory school attendance covers ages 7 to 21/23 years old.</td>
</tr>
<tr>
<td>1950s and 1960s</td>
<td>Special boarding school is the predominant service for children and youth with cognitive impairments (approximately 3,000 places at its peak). However, the severely &quot;retarded&quot; pupils with additional impairments are excluded from regular schooling (approximately 6,000 children).</td>
</tr>
<tr>
<td>1956</td>
<td>The start of school classes for children with visual impairments in Stockholm and Gothenburg.</td>
</tr>
<tr>
<td>Year</td>
<td>Event</td>
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<tr>
<td>---------</td>
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</tr>
<tr>
<td>1962</td>
<td>The Act concerning compulsory school attendance is revised to include children with mobility impairments. The municipalities are responsible for providing schooling.</td>
</tr>
<tr>
<td>1965</td>
<td>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.</td>
</tr>
<tr>
<td>1967</td>
<td>The start of the national upper secondary school for deaf youth in Örebro.</td>
</tr>
<tr>
<td>1968</td>
<td>The Care Act is revised, and the issue of schooling for children and youth with cognitive impairments is moved into the Education Act.</td>
</tr>
<tr>
<td>1968</td>
<td>Compulsory school attendance/legal right to schooling for children with cognitive impairments is enacted. The regulation of the special school is moved into the Education Act.</td>
</tr>
<tr>
<td>1969</td>
<td>The teaching program for primary school applies to the integration of everyone in ordinary classes.</td>
</tr>
<tr>
<td>1970/1971</td>
<td>The start of adult schooling for persons with cognitive impairments as a pilot scheme (primary and training school level).</td>
</tr>
<tr>
<td>1970s and 1980s</td>
<td>Special boarding schools and care homes for children are closed. Pupils' homes gradually replace special boarding schools.</td>
</tr>
<tr>
<td>1971</td>
<td>Eugeniahemmet is closed. Disabled children must be admitted to municipal schools.</td>
</tr>
<tr>
<td>Year</td>
<td>Event</td>
</tr>
<tr>
<td>--------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1979</td>
<td>Norrbackainstitutet is closed and replaced by inclusion in municipal schools.</td>
</tr>
<tr>
<td>1981</td>
<td>The parliament recognises sign language as the first language for Deaf persons.</td>
</tr>
<tr>
<td>1984</td>
<td>The start of the national upper secondary school for youth with hearing impairment in Örebro.</td>
</tr>
<tr>
<td>1986</td>
<td>The Tomteboda school is closed and replaced by inclusion in municipal schools.</td>
</tr>
<tr>
<td>1988 – 1996</td>
<td>Municipalisation of the special school. Admission without consent is replaced by on demand for attending special primary school, special upper secondary school and adult schooling.</td>
</tr>
</tbody>
</table>
Annex 2 - Table – The institutional era and its ending

The table “the institutional era and its ending” 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 “uneducable” and “crippled” to being enabled to leave the large institutions and move into own dwellings in the community.

<table>
<thead>
<tr>
<th>Period/Year</th>
<th>Reform/Activity/Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1788</td>
<td>An ordinance gives the parish the right to refuse occupation for “ihysehjon” (lodged paupers) and older and less able to work “tjänstehjon” (living-in lower rural workers).</td>
</tr>
<tr>
<td>1847</td>
<td>An ordinance on the legal right to poor relief is enacted.</td>
</tr>
<tr>
<td>1866</td>
<td>Opening of the first home for ”sinneslöa” (the slow of sense).</td>
</tr>
<tr>
<td>Start of the</td>
<td>Persons with cognitive impairments are viewed as uneducable and must be protected against society, and society must be protected against them. The ideology of eugenics is prevailing.</td>
</tr>
<tr>
<td>1900s</td>
<td></td>
</tr>
<tr>
<td>1913</td>
<td>The parliament adopts universal pension insurance.</td>
</tr>
<tr>
<td>1915</td>
<td>The law on impediments to marriage is enacted.</td>
</tr>
<tr>
<td>1918</td>
<td>The law (1918:422) on poor relief is enacted.</td>
</tr>
<tr>
<td>Start of the</td>
<td>“Vanföreanstalter” (school institutions for cripples) are organised; from the end of the 1800s, school homes were built and annexed to institutions.</td>
</tr>
<tr>
<td>1900s</td>
<td></td>
</tr>
<tr>
<td>Year</td>
<td>Event</td>
</tr>
<tr>
<td>--------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>1920s and 1930s</td>
<td>The start of “Sinnesslövård” (care of persons with cognitive impairments) with special hospitals and institutions for “the slow of senses” and the mentally ill.</td>
</tr>
<tr>
<td>1930s</td>
<td>The housing allowances were introduced in the middle of the 1930s and got their current form in 1997.</td>
</tr>
<tr>
<td>1934</td>
<td>The blind allowance (later invalid allowance) is introduced. Recently known as the disability allowance.</td>
</tr>
<tr>
<td>1935</td>
<td>The law on forced sterilisation is introduced and includes, among others, certain disabled persons. The law was abolished in 1975.</td>
</tr>
<tr>
<td>1940s</td>
<td>Families with children with cognitive impairments are advised to hand over and forget the child. The advice is, for example, written in “Hemnets Läkarebok” (Doctor’s advice for the home) from 1949.</td>
</tr>
<tr>
<td>1945</td>
<td>Persons cared for by the “poor relief” get the right to vote.</td>
</tr>
<tr>
<td>1948</td>
<td>Child benefit is introduced.</td>
</tr>
<tr>
<td>1948</td>
<td>Invalid pension and sick benefits (later early retirement/sickness benefit and from 2003 sickness/activity benefit) are introduced.</td>
</tr>
<tr>
<td>1950s</td>
<td>Institutional care is prevailing. A substantial expansion of 40 large institutions with approximately 200 places on average is taking place.</td>
</tr>
<tr>
<td>1955</td>
<td>Schooling and care of persons with cognitive impairments are transferred to the county councils, but special hospitals and special care homes remain under the government’s responsibility.</td>
</tr>
<tr>
<td>Year</td>
<td>Event Description</td>
</tr>
<tr>
<td>---------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1955</td>
<td>Universal sick insurance, income-related sickness benefits and subsidised medical care are introduced.</td>
</tr>
<tr>
<td>1956</td>
<td>A law reform establishes that social benefit is replacing poor relief.</td>
</tr>
<tr>
<td>1960</td>
<td>National supplementary pension is introduced.</td>
</tr>
<tr>
<td>1960s and 1970s</td>
<td>The expansion of another 40 institutions takes place to manage the queue to institutional placement. There were a total of 180 institutions in Sweden when there were no longer any waiting lists for placement in 1980.</td>
</tr>
<tr>
<td>1960s</td>
<td>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”. “Vanföreanstalter” (school institutions for persons with mobility impairments) start closing.</td>
</tr>
<tr>
<td>1965</td>
<td>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 dwellings for children and youth with mobility impairments. The number of school institutions is decreasing. The first national upper secondary school starts.</td>
</tr>
<tr>
<td>1960s</td>
<td>The expansion of “Fokushus”/housing with services for persons with mobility impairments kicks off with a national telethon.</td>
</tr>
<tr>
<td>1966</td>
<td>Car allowance is introduced.</td>
</tr>
<tr>
<td>Year</td>
<td>Event</td>
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<tr>
<td>------</td>
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</tr>
<tr>
<td>1968</td>
<td>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.</td>
</tr>
<tr>
<td>1968</td>
<td>Permobil/electric wheelchair becomes free of charge mobility aid.</td>
</tr>
<tr>
<td>1970s</td>
<td>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.</td>
</tr>
<tr>
<td>1974</td>
<td>Parental insurance is introduced.</td>
</tr>
<tr>
<td>1982</td>
<td>The Social Care Act includes a paragraph concerning support for disabled persons.</td>
</tr>
<tr>
<td>1984</td>
<td>A national special transport service is introduced.</td>
</tr>
<tr>
<td>1985</td>
<td>The Education Act regulates preschool classes, primary schools, upper secondary schools, special schools and the Saami school – the public education system for children and youth. 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.</td>
</tr>
<tr>
<td>1986</td>
<td>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 close to 200 existing institutions. However, a final date is not set.</td>
</tr>
<tr>
<td>1985</td>
<td>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.</td>
</tr>
<tr>
<td>Year</td>
<td>Event</td>
</tr>
<tr>
<td>------</td>
<td>-------</td>
</tr>
<tr>
<td>1989</td>
<td>The Disability Committee of 1989 was appointed. It resulted in the LSS reform in 1994.</td>
</tr>
<tr>
<td>1993</td>
<td>The responsibility for care under the Care Act (for persons with cognitive impairments) is transferred from the county councils/regions to the municipalities.</td>
</tr>
<tr>
<td>1994</td>
<td>The right to personal assistance is introduced when the Act concerning Support and Service to Certain Persons with Functional Impairments, LSS, comes into force. And 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.</td>
</tr>
<tr>
<td>1994</td>
<td>The Care Act is replaced by the Act concerning Support and Service to Certain Persons with Functional Impairments, LSS. The target group is widened to include children, youth and adults belonging to one of three subcategories of the target group, regulated under the law. There are ten support services regulated under LSS.</td>
</tr>
<tr>
<td>1995</td>
<td>The Psychiatric Reform is implemented. Compulsory psychiatric care at so-called mental hospitals is to be closed down.</td>
</tr>
<tr>
<td>1997</td>
<td>A specific Act concerning the closure of special hospitals and care homes introduces compulsory closing of institutions before 2000. The one existing special hospital closed immediately in 1997. The closer to 1000 individuals living in the existing 52 care homes move out to their respective municipalities and into suitable dwellings, included in the community.</td>
</tr>
<tr>
<td>Year</td>
<td>Description</td>
</tr>
<tr>
<td>------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1997 and forward</td>
<td>Planning and expanding group homes and housing with services under LSS are ongoing. Move out of institutions to own dwellings, mainly in housing with special services under LSS, are underway.</td>
</tr>
<tr>
<td>2008</td>
<td>The Discrimination Act includes disability as one of its grounds for discrimination.</td>
</tr>
<tr>
<td>2009</td>
<td>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.</td>
</tr>
<tr>
<td>1999/2000</td>
<td>“Från patient till medborgare” or From Patient to Citizen – the Swedish disability policy was adopted and to be implemented from 2000 – 2010 with the CRPD as a foundation.</td>
</tr>
<tr>
<td>2010</td>
<td>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.</td>
</tr>
<tr>
<td>2016/2017</td>
<td>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).</td>
</tr>
</tbody>
</table>

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

Inger Persson Bergvall och Malena Sjöberg, Åratal ur handikapphistorien, (HandikappHistoriska Föreningen 2012).

Karl Grunewald, Omsorgsrevolutionen (Intra 2015).

Karl Grunewald, Från idiot till medborgare (Gothia Förlag AB 2008).
Annex 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 spread to Europe. Today, it is a global movement. IL is important for us disabled persons. We spend our lives promoting 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 having access to our rights.

Independent Living - a movement

Independent living is a movement of disabled persons that started in the US in the 1960s. 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 and IL- organisations in Sweden. 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, i.e. that the movement is for everyone who is disabled no matter what impairments. To view disability issues from a social perspective and as rights, instead of 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, i.e. 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. ¹⁸²

The IL movement promoted these rights long before the CRPD came onto the scene, 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 widened the movement. ¹⁸³ 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 have in their daily lives, i.e. 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 and have employment in line with their interests and acquired education. Disabled persons want, like most others, to start a family but may need social services with certain practical chores.

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

¹⁸³ Adolf Ratzka, What is Independent Living (Independent Living Institute 2005)
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, 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. 184 Exchanging experiences 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 what to do by others.”

The principles of independent living were adopted on the 3rd of September 1990 at a European Network for Independent Living (ENIL) meeting held in Holland. 185 The IL movement was represented in forming the UN Convention on the Rights of Persons with Disabilities (CRPD) and succeeded in influencing the text of article 19 of CRPD and the general comment number 5.

184 Adolf Ratzka, The Origins of ENIL – as recollected by Adolf Ratzka, ENILs Founding Chair (European Network of Independent Living, Hall of Fame 2013)
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 is to have 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, and 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 table cloth and candle lights on the table, have pets or listen to music. These are the actions and decisions that make us into 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 opportunity to choose and control their personal lifestyle and daily activities. 186

Attempts are made to "kidnap" the independent living terminology and use it with a different meaning than the one in the independent living philosophy. Different actors at the EU level and various national levels can, for example, talk about personal assistance for residents in

186 https://www.mfd.se/contentassets/10cb4a4f8e34299beb96d965c77e8fb/2020-2-all-man-kommentar-5-sjalvstandigt-liv-inkluderad-i-samhallsgemenskapen.pdf
institutions. Therefore, ENIL found it necessary to define important concepts, including independent living, personal assistance, deinstitutionalisation and community-based services.\textsuperscript{187}

The definition provided for independent living is: \textit{“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 to live, with whom to live and how to live. Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing 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 the gender, age and the level of their support needs.”}

**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.\textsuperscript{188}

**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 society’s social, political and economic life. The more help from others is needed, the more individuals risk being subjected to paternalism, overprotection and discrimination. One of IL’s goals is to have laws and legal practise in all countries making discrimination on the ground of disability illegal.

\textsuperscript{187} \url{https://enileu/independent-living/definitions/} accessed 24 Januari 2021

\textsuperscript{188} Adolf Ratzka, The Origins of ENIL – as recollected by Adolf Ratzka, ENIL’s Founding Chair (European Network of Independent Living, Hall of Fame 2013)
**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 dwellings 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**

Independent living views institutionalisation from a considerably wider perspective than certain individuals in the community being allowed to live in a building especially designated for them. Independent living means that all humans shall be included in the community, no matter their functionality. 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, i.e. the pursuit of building and developing of goods and services usable for everyone, no matter their functionality. 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
individuals in white coats. The more comprehensive the impairment is, the sicker the individual is in the eyes of the surroundings, and the more professional education is assumed to be needed. In this way, society has transferred the control over disabled persons’ lives to professionals. Many believe a doctor or social worker is best qualified to make decisions on disabled persons’ lives. The more power transferred to the individual in 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 and talk about how they should live their lives and what they need from society to fulfil their obligations as family members and citizens. Non-disabled persons can be allies in the struggle for equal rights. Nothing about us without us!

**The Independent Living movement**

In the 1960s and 1970s US political climate, coloured by ethnic minorities demanding their equal rights, disabled persons began to organise. Among the leaders of initiatives in a number of 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 discrimination\(^\text{189}\) and were joined by other disabled persons in Europe and other parts of the world fighting for the same cause.\(^\text{190}\) They wanted to change the world so disabled children and adults would not have to encounter the same obstacles they had to face against marginalisation and have to live in institutions or be

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\(^{189}\) Judith Heumann with Kristen Joiner, Being Heumann – an unrepentant memoir of a disability rights activist (Beacon Press 2020)

\(^{190}\) Jane Campbell and Mike Oliver, Disability Politics – Understanding our past, changing our future (Routledge 1996)
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 blocked opportunities, as in Judith’s case becoming a teacher. They demanded social services based on their needs. Independent living works against discrimination and oppression and works for human rights, participation, political and personal power where the medical diagnosis is not important, but the focus lies on the access to rights based on individual needs.

Adolf Ratzka is, as mentioned before, one of the individuals who has been 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 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 should 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). In Sweden, Adolf was provided support from the home care services when the money connected to his research ran out, and he paid the price of once again losing his self-determination.

**Stockholm Cooperative for Independent Living (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 paid

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191 Ritva Gough, Personlig Assistans – en social bemästringsstrategi (Ritva Gough & GIL-förlaget 1994)
directly to the assistance user. The group organised itself into an association, the Stockholm Cooperative for Independent Living (STIL) which started in 2014. 192

STIL negotiated a pilot project based on the STIL’s service model with the City of Stockholm to provide personal assistance. The assistance users in the project recruited, trained, negotiated salaries, decided on working schedules, 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). With personal assistance as a civic 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 and deinstitutionalisation and provision and control of services led by disabled persons themselves.193 CILs were established first in the US194 and later in European countries and worldwide.195 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 and disabled persons being considered sick instead of ordinary human beings, as emphasised in the CRPD.196 The social model of disability is promoted.197

192 [https://www.stil.se/](https://www.stil.se/)
193 John Swain, Sally French and Colin Cameron, Controversial Issues in a Disabling Society (Open University Press 2003)
194 Andrew Power, Janet E. Lord and Allison S. deFranco, Active Citizenship and Disability (Cambridge University Press 2013)
196 Mary Crock, Laura Smith-Khan, Ron McCallum and Ben Saul, The Legal Protection of Refugees with Disabilities – Forgotten and invisible? (Edward Elgar Publishing Limited 2017)
197 Colin Barnes, Theories of disability and the origins of the oppression of disabled people in the western society (Longman Sociology Series 1996)
**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. Seventy-two disabled persons from more than 20 countries were present. It was decided to start the European Network of Independent Living (ENIL) at this meeting, 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 current issue that has gained interest and resulted in activities carried out by several CILs in 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.

**Independent Living Institute (ILI) in Stockholm**

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198 Adolf Ratzka, The Origins of ENIL – as recollected by Adolf Ratzka, ENILs Founding Chair (European Network of Independent Living, Hall of Fame 2013)
199 [https://enil.eu](https://enil.eu)
200 [https://www.independentliving.org](https://www.independentliving.org)
The Independent Living Institute (ILI) was founded by Adolf Ratzka and Rolf Bergfors in 1993, when the cooperative STIL, providing personal assistance, was working well. The idea was to pursue other projects to promote independent living and rights for disabled persons in Sweden and 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** is the project that has had the most impact. It was started as a project funded by the Swedish Inheritance Fund (2007-2010) but has since developed and is now almost wholly funded by advertising revenue. Assistanskoll is a website with possibilities to compare different assistance providers, a large database and 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** (Law as 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** (Article 19 as 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 CRPD and the general comment number 5.

**Disabled Refugees Welcome** aims to improve the reception of disabled migrants into the Swedish community. The project attracted a lot of interest through its intersectional approach,

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201 [https://www.independentliving.org](https://www.independentliving.org)
202 [https://assistanskoll.se/](https://assistanskoll.se/)
203 [https://lagensomverktyg.se/](https://lagensomverktyg.se/)
204 [https://lagensomverktyg.se/](https://lagensomverktyg.se/)
205 [https://disabledrefugeeswelcome.se/](https://disabledrefugeeswelcome.se/)
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 in the area of integration, migration and disability.

Anmälningstjänsten\textsuperscript{206} (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\textsuperscript{207} (Personal assistance tips), which gather tips formulated by assistance users directed to other assistance users about making your assistance function in the best possible way.

Fashion Freaks\textsuperscript{208} has had a large international impact with its collection of basic patterns and instructions adapted for wheelchair users.

Disability Rights Defenders\textsuperscript{209} is an international network to exchange legal expertise 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\textsuperscript{210} (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 seven European cities with local partner organisations; ILI is responsible for the Stockholm working group.

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{206} https://anmalningstjansten.se/
\item \textsuperscript{207} https://patips.se/
\item \textsuperscript{208} https://fashionfreaks.se/
\item \textsuperscript{209} https://www.independentliving.org/drd/
\item \textsuperscript{210} https://trips-project.eu/
\end{itemize}
\end{footnotesize}
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 Norway211, Threshold in Finland212 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.

211 https://www.uloba.no/
Annex 4 – ENILs Principles of Independent Living

Principles of Independent Living

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

These principles 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. In order 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.

213 These principles were adopted at the ENIL meeting, “Het Timmerholt”, Netherlands August 31 – September 3, 1990
5. Disabled people must obtain all the requirements for equalisation 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
Annex 5 – The Strasbourg Resolution

In April 1989, the first European Independent Living Conference was held at the European Parliament in Strasbourg, France. The meeting’s theme was Personal Assistant. 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 from April 12-14 1989 at the European Parliament, Strasbourg, France. This conference has focussed on Personal Assistance Services as an essential factor of Independent Living, which itself encompasses the whole area of human activities, e.g. 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 disable people

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214 [https://www.independentliving.org/docs2/enilpakeytoil.html](https://www.independentliving.org/docs2/enilpakeytoil.html)
Keynote address to the conference on personal assistance in Strasbourg

215 [https://www.independentliving.org/docs2/enilstrasbourgresolutions.html](https://www.independentliving.org/docs2/enilstrasbourgresolutions.html)
Resolutions
in 1985) and consider that a key prerequisite to this civil right is through Independent Living and the provision of support such as personal assistant services for those who need them.

The recommendations of the UN World Programme of Action (Paragraph 115) specifically 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 policy-makers 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.

Source: European Network on Independent Living, ENIL  https://enil.eu/