

Understanding Independent Living in Sweden: An Overview

By: Alexander Caputo Janhager

May 2019

Table of Contents

1) Introduction
2) What is the Independent Living Institute (ILI)?
2.1 History of Independent Living: The Journey to Establishing ILI
2.2 Independent Living: A Philosophy & Movement
2.3 The Independent Living Institute's Mission
2.4 Selection of Past Projects
2.5 Current Projects
Article 19 as a Tool:
Disabled Refugees Welcome:
3) Sweden's Political System
3.1 Potential Repercussions of Recent Changes to the Swedish Political Landscape9
3.2 Levels of Government and the Division of Functions
3.3 History of Swedish Elections: A Brief Analysis16
3.4 Electoral System & Political Parties17
3.5 Proposal for a New Strategic Disability Policy
4) Sweden's Legal System
4.1 Legislative process in Sweden
4.2 Application of EU laws in Sweden21
4.3 Relevant Laws and International Conventions Regarding Independent Living22
5) The Council of Europe and UN as Influencing Bodies
5.1 European Court of Human Rights vs. UN Committee on the Rights Persons with Disabilities
5.2 Office of the High Commissioner for Human Rights: Relevant Conventions25
UN Convention on the Rights of Persons with Disabilities (CRPD)26
UN Convention on the Rights of the Child (CRC)26
Bibliography

1) Introduction

Independent Living has a tightly intertwined relationship with both the political and legal systems in Sweden. There is a continuous dialogue between non-governmental organizations like the Independent Living Institute (ILI), and State institutions when pursuing the settlement of political, legal and social conflicts regarding disability rights. Understanding the basic functions of political and legal institutions in Sweden assists in understanding the issues and challenges for Independent Living as philosophy and movement in Sweden. Further, key historical events have significantly impacted on politics, laws and social ideologies regarding Independent Living in Sweden and the European Union (EU).

The main purpose of this document is to provide a collection of information that will help to build a basic foundation of knowledge regarding the Independent Living Institute as an organization, the political and legal systems in Sweden, and the functions of overarching international institutions that influence the Independent Living Institute's work.

2) What is the Independent Living Institute (ILI)?

2.1 History of Independent Living: The Journey to Establishing ILI

Before 1990, people with extensive disabilities in Sweden had few options when it came to housing and daily support. Institutions for people with disabilities began to disappear and the home became an institution. The care offered by home-helper services restricted disabled people's lives and prevented them from taking their equally rightful place as fully participating in their families and in society. Adolf Ratzka (2012) suggests "the home-helper and cluster-housing services essentially meant house arrest for people who needed physical assistance throughout the day, regardless of location."¹ Instead of assisting people with disabilities to assume rightful control and choice in order to achieve self-determination, equal opportunities and self-respect, these services forced people with disabilities to become dependent on the services.

While people living with disabilities in Sweden were experiencing these difficulties, the Independent Living movement emerged in the United States. The Independent Living philosophy informs the Independent Living movement with its core premise to empower disabled people using four key concepts: freedom, choice, control, and equality.² Independent living means to have the freedom to make choices about the types and means of support that are required for an individual living with a disability to obtain rightful and equal control in their day-to-day life just as for able-bodied persons.

The Independent Living movement rose to new heights thanks in part, to the efforts of Ed Roberts. Roberts, who had been diagnosed with polio at the age of 14, uses a wheelchair since becoming paralyzed from the neck down.³ In 1962, he started his studies at

³ About. (n.d.). Retrieved from Ed Roberts Campus website:

¹ Ratzka, A. (2012). The Independent Living movement paved the way: Origins of

Personal assistance in Sweden. Retrieved from Independent Living Institute website: https://www.independentliving.org/docs7/Independent-Living-movement-paved-way.html

² Hasler, F. (2003). Philosophy of Independent Living. Retrieved from Independent

Living Institute website: https://www.independentliving.org/docs6/hasler2003.html

the University of California Berkeley where he became the first student to have significant disabilities. At the time, there was no housing for students with disabilities leaving institutionalization as the only option. Inspired by the political activism movements for racial equality in the 1960's, twelve students, including Roberts, who were forced to live in Berkeley's Cowell Hospital infirmary, formed a group called The Rolling Quads out of their shared struggles with discrimination and physical barriers. The Rolling Quads began to realize that living in an institution was unacceptable, as it denied them to fully live their lives. Their association with the hospital stigmatized the Rolling Quads; they became known as "students during the day and patients by night."⁴

Realizing that living in Cowell was not a long-term solution for members of The Rolling Quads as well as for future severely disabled students, the group began to organize a support group to help people with disabilities to live independently. The Rolling Quads submitted a grant proposal requesting funds from the Department of Health, Education and Welfare to create The Physically Disabled Students' Program (PDSP) at Berkeley. They received the grant funds in 1970 and PDSP opened their first office on campus. The purpose was to help disabled students live independently and to offer support to prevent them from being pushed into dropping out of school because of inadequate services and accommodations to support their success. This radical student organization grew and redefined normative definitions of independence to counter medical models of disability that only focused on providing forms of custodial help. The PDSP saw independence as measurable by the amount of control a disabled person had over their life. PDSP and the Independent Living movement began to reach individuals outside of the school system. The movement began to expand and grow.⁵

In 1972, Ed Roberts and other PDSP leaders came together to establish the first Center for Independent Living (CIL) in Berkeley, California as a parallel system to PDSP, but for non-students. The CIL later became the global model for all subsequent Independent Living organizations. The model featured programs run by disabled people for disabled people, and an approach to personal problems as social issues as a means of achieving fluid integration into the community. The Independent Living movement spread out across the United States, something that was unthinkable considering the long history of harsh treatment towards people with disabilities in the United States.⁶

At the height of the Independent Living movement in the United States during the early 1970's, Adolf Ratzka, having contracted polio at a young age similar to Ed Roberts, and who was also a student at the University of California Berkeley noticed that he was finally able to choose and control decisions over his own life and receiving the services that he needed to succeed at the university. These experiences at Berkeley were vastly different from his time living and studying in Europe. In 1983, Ratzka organized an international conference in Stockholm involving key figures in the U.S. Independent Living movement. They presented the key approaches and ideology behind Independent Living to colleagues from

⁶ Ibid.

https://www.edrobertscampus.org/about/

⁴ The information in this paragraph is from:

Shapiro, J. P. (1993). No Pity: People with Disabilities Forging a New Civil

Rights Movement. New York, USA: Times Books, 41-58.

⁵ Ibid.

Sweden, Norway and Denmark. In 1984, resulting from the Stockholm conference, a nonprofit organization using the CIL Independent Living model was established; it was called the Stockholm Cooperative for Independent Living (STIL).⁷

Shortly after STIL began its operations, they started a pilot project to demonstrate how personal assistance delivered both better quality with cost savings over other previous service forms. This immediately caught the attention of politicians, specifically Bengt Westerberg, who was a member of the Liberal People's Party in Sweden. When Westerberg became the Minister of Social Affairs in the early 1990's, he demonstrated his strong belief in the principles of Independent Living by pushing forward laws that gave disabled people the right to personal assistance. After this victory in the political realm, STIL began to focus to advance self-determination, freedom, and equal opportunity for all persons with disability. In the 1980's, STIL received an influx of media attention for they became a political force in the debate concerning division of roles between the State and the individual in welfare production and the question of who is better positioned to ensure maximum welfare. This attention allowed STIL's membership and activities to drastically increase. STIL founded the European Network on Independent Living (ENIL) in 1989 to serve as a community of organizations with the common goal to spread the Independent Living philosophy and personal assistance initiative as the tools necessary to replace existing institutional solutions both within and outside of Europe.8

As a pioneer in the European chapter of the Independent Living movement, Adolf Ratzka founded the Independent Living Institute (ILI) through STIL and GIL (Gothenburg Cooperative for Independent Living) in 1993. The initial purpose of the ILI was to serve as a national and international "think tank" dedicated to issues regarding self-determination and personal assistance. Since 1993, the Independent Living Institute has grown from a small organization to developing a vast network of contacts and garnering international recognition. It has developed several projects that all work towards the collective goal to promote disabled peoples' personal and political power. In the past few years alone, the success of ILI's projects has strengthened the organization and raised its visibility and reputation as a respected organization in the disability movement.⁹

2.2 Independent Living: A Philosophy & Movement

Independent Living Philosophy:

Four main principles inform the Independent Living philosophy: freedom, choice, control, and equality. While experts in the disability movement hold slightly different definitions of 'independent living,' although they all contain these four principles as a common denominator. In essence, 'independent living' means to have the freedom to make choices about the types and means of personal support that are required to obtain rightful and equal control in day-to-day life as do able-bodied persons.¹⁰

Ratzka, A. (2003). Independent Living in Sweden. Retrieved from Independent

Living Institute website: https://www.independentliving.org/docs/Independent_Living_in_Sweden.html#origins

⁸ Ibid.

9 Ibid.

⁷ The information in this paragraph was taken from:

¹⁰ Hasler, supra note 2.

Additional examples of definitions of 'independent living' provided by community members:¹¹

"It is the ability to live independently and productively in the community and to live with the same freedom of choice as a non-disabled person. So it's not that you are living on your own but that you control where you live and have the same range of choices as a non-disabled person." (Jill Weiss)

"'Independent living' means the ability to examine alternatives and make informed decisions and direct one's own life. This ability requires the availability of information, financial resources and peer group support systems. 'Independent living' is a dynamic process; it can never be static. A person's physical, emotional and social environment and subsequent needs are continually changing and evolving. The struggle for independent living and personal determination is something each disabled person must approach in their own way. However, as disabled persons, we have common problems and concerns and we must continue to work together to eliminate artificial barriers to our full and equal participation in society." (Michael Huck)

"'Independent living' really is an idea, a concept, a thought process. You apply this thought process to your lifestyle. I would think that even if a person were in prison and the only choice that they could make would be whether they would eat their food when they first got it, or eat it an hour later, they would still be practicing Independent Living." (Elizabeth Semkiw)

The Independent Living Movement:

The Independent Living movement puts this philosophy into practice. There are various forms that the movement takes depending on the type of work being produced by a particular organization, group or individual. The European Network on Independent Living (ENIL) plays a major role in facilitating the European chapter of this movement by connecting people in forty countries working towards the common goal of spreading the Independent Living philosophy.¹²

2.3 The Independent Living Institute's Mission

"The Independent Living Institute (ILI) is a policy development center specializing in consumer-driven policies for disabled peoples' freedom of choice, self-determination, self-respect and dignity. Our ultimate goal is to promote disabled people's personal and political power. Towards this end we provide information, training materials and develop solutions for services for persons with extensive disabilities in Sweden and internationally. We are experts

¹¹ The following three quotes have been directly taken from:

Ratzka, A. (1992). What is your personal definition of Independent Living?.

Retrieved from Independent Living Institute website: https://www.independentliving.org/toolsforpower/tools11.html

¹² ENIL, the European Network on Independent Living: Documents. (1999). Retrieved

from https://www.independentliving.org/docs2/enildocs.html#anchor862229

in designing and implementing direct payment schemes for personal assistance, mainstream taxi and assistive technology."¹³

2.4 Selection of Past Projects¹⁴

i) The Law as a Tool for Social Change ("Law as a Tool")

The Law as a Tool for Social Change project successfully achieved its goal to raise awareness on the issue of discrimination against disabled people. It made ILI a forerunner in the Swedish Disability Movement. Running from March 2016 to February 2019, the project attained its mission by providing legal assistance to people with disabilities and general assistance to attorneys taking on disability cases by offering education and support. Emil Erdtman led the project with legal representation by Ola Linder. Outcomes of this project are represented in case law, an international conference, comments on the draft of General Comment 6, and a communication to the Committee on the Rights of Persons with Disabilities.

For more information about The Law as a Tool for Social Change, see https://www.independentliving.org/taxonomy/term/48

ii) Assistanskoll / Personal Assistance Watch

As ILI's focus on comparative consumer information for personal assistance began to gain support from the Swedish Consumer Agency, they were granted funding from the Swedish Inheritance fund to conduct the Assistanskoll project between 2007 and 2010. The purpose of this project was to create an online database comprised of information, facts and numbers, analyses and advice for assistance users, their families and assistants in the selection process of assistance providers. Since there are always changes in legislation, political debates, case law, and the market, the Assistanskoll services help to keep the public aware of these shifts. After the project funding ended in 2010, Assistanskoll continued to grow and develop. The Independent Living Institute's 2017 Annual Report demonstrates this overall growth by confirming an 18% increase in website views from 2016 (686,000 in 2016 to 809,000 in 2017).

For more information on Assistanskoll, see <u>https://assistanskoll.se/om-assistanskoll.html</u> (webpage is in Swedish)

2.5 Current Projects¹⁵

¹⁵ In addition to the referenced website, the information in section 2.5 has been taken from:

¹³ Independent Living Institute (2019). About the Independent Living Institute (ILI). Retrieved from Independent Living Institute website: https://www.independentliving.org/about.html

¹⁴ In addition to the referenced websites, the information in section 2.4 has been taken from:

Independent Living Institute. (2018). Action Plan 2017-2019. Retrieved from Independent Living Institute website: http://independentliving.org

Article 19 as a Tool:

This project is a three-year effort (April 2019 – March 2022) funded by the Swedish Inheritance Fund that will contribute to the implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) with specific reference to the right to living independently and the right to being included in the community. The General Comment on Article 19 (GC 5), adopted by the UN Committee in 2017, has actualized this project. The GC 5 raises the overarching question of whether Sweden truly complies with Article 19 of the UNCRPD.

The project is being carried out together with the Raoul Wallenberg Institute. There are three parts within the project that are divided into two group types. A 'reference group' consisting of authorities and organizations that will have a linking function advance the project by connecting it to other ongoing monitoring and implementation activities. The other group is the 'special group' that will steer the development work of the follow-up tool. The follow-up tool is primarily used to test the extent to which the UNCRPD has been implemented. It can also be used by individuals to assess their level of self-determination.

The three parts of this project are:

- 1. Awareness-raising about the UNCRPD and Swedish law to strengthen selfconfidence and empowerment among people with disabilities
- 2. Usage of the 'Follow-Up Tool' for assessing how Sweden complies with the requirements of Article 19 of the UNCRPD.
- 3. Contributing to guiding analyses of Swedish Law to ensure compliance with practical and theoretical implementation of the rights stated in Article 19

Disabled Refugees Welcome:

"DRW wants to achieve an including society and equal opportunities for independent living for everyone regardless functional ability or number of years spent in Sweden."

The idea for the Disabled Refugees Welcome project was born as a result of project worker Julius Ntobuah's own experiences as an asylum seeker with disability in Sweden and has no predecessor. This project is important because it helps to address certain issues that have arisen following an influx of over 162 000 asylum seekers came to Sweden during 2015. Even today the inflow of people continues and many are in need of urgent support with food, accommodation, medical care and psychological support after previous traumatizing experiences. Moreover there are many who got either injured during the war and the long or dangerous way to Europe or had disability since before.

The goal of Disabled Refugees Welcome (DRW) is to improve the reception of disabled asylum seekers and their integration into Swedish society through development, testing and application of a method of reception for disabled asylum seekers. The ultimate mission will be to formulate the method of reception that can be taken over by authorities and

Independent Living Institute. (2018). Action Plan 2017-2019. Retrieved from Independent Living Institute website: http://independentliving.org

voluntary organizations, to become an obvious part of their general work with asylum seekers.

The project should therefore:

- i) Inform disabled asylum seekers about their rights and the support of authorities and non-governmental organizations.
- ii) Assist disabled asylum seekers to pursue the support they feel they need.
- iii) Collect and disseminate statistics on the perceived needs of disabled asylum seekers.
- iv) Develop and test a method for receiving disabled asylum seekers to be spread to public and private actors working with asylum seekers.

The project is funded by the Swedish Inheritance Fund during the period of September 2017 -August 2020.

For more information on Disabled Refugees Welcome, see: https://disabledrefugeeswelcome.se/en/

3) Sweden's Political System

3.1 Potential Repercussions of Recent Changes to the Swedish Political Landscape

The political landscape in Sweden has changed sporadically for decades. Some of the challenges that the Independent Living Institute (ILI) faces in its various projects are linked with the Swedish political system. In conducting their work, ILI attempts to foresee and anticipate potential political conflicts and challenges that may arise from the type of work they undertake.

Sweden's political landscape over the past 35 years has experienced two major changes: the introduction of new political parties and Sweden's membership in the European Union (EU) in 1995. Traditionally, there were five political parties ranging between two opposite points on the left-right scale. Since 1988, three additional political parties have either been created or received a significant increase in their membership. These additional parties present challenges to the ideologies of the five original parties. For instance, in 1981, the newly founded Green Party brought their focus on recognizing environmental issues; by 1988, these issues were becoming more popular with the general public. A second 'new' political party founded in 1988 was the Sweden Democrats, a socially conservative party based on nationalism. The party did not gain seats in parliament until 2010. The Christian Democrats, founded in 1964, are the third party having a major breakthrough in 1991 when they gained 7.1% of votes. The Christian Democrats use democratic ideology to bring Christian values into politics. The growth of these three political parties over the past 35 years

contribute to the variances and complexities of Sweden's changing political landscape that, in turn, have implications for persons living with disabilities in Sweden.¹⁶

See subsection "Electoral System" for more information on each of the eight political parties.

In addition to the introduction of new political parties to Sweden's political landscape, a second major change has been the country's membership in the European Union (EU). In 1995, Sweden joined the EU. This move brought forward several institutional changes to governance structures that modified the process and scope of political actions conducted by State actors. The EU serves as a politically influential and legally binding body of institutions that function external to Sweden as a state, but has effects that are reflected internally. Sweden's membership to the EU allows for an increasing engagement of non-state actors becoming involved in the Swedish political scene, leading to a decrease in membership of political parties and trade unions.¹⁷ There are four main EU institutions that influence Sweden as a state, and therefore also affect the work being conducted at the Independent Living Institute:

1. <u>The European Parliament¹⁸</u>

The predecessor of the European Parliament was the Parliamentary Assembly of the European Coal and Steel Community that came into effect on July 26, 1952 after the ratification of the Treaty of Paris on April 18, 1951. Over time, there has been a trend towards the legal empowerment of the Parliamentary Assembly to become The European Parliament (EP). Today's EP is a directly elected EU body comprised of 751 Members. The EP has three core functions: First, shared legislative powers with the European Council; Second, shared budgetary powers with the European Council; and third, the power to control all EU institutions, more specifically the European Council. The powers of the European Parliament were advanced further on December 1, 2009, when the Lisbon Treaty –ratified on December 13, 2007, - came into force. The main function of the Lisbon Treaty is to establish equal law-making powers between the EP and the European Council that did not previously exist for all matters.

Elgenius, G., & Wennerhag, M. (2018). The changing political landscape in Sweden. *Sociologisk Forskning*, 139-154.

17 Ibid.

¹⁶ The information in this paragraph is taken from:

¹⁸ European Parliament Timeline. (n.d.). Retrieved from European Parliament Timeline

website: http://www.europarl.europa.eu/about-parliament/en/in-the-past

See the European Parliament website for more information: <u>http://tinyw.in/POII</u> ...

2. The Council of the European Union ('The Council')¹⁹

The Council is a core decision-making body of the European Union that works co-operatively with the European Parliament to execute Acts in a legislative and budgetary capacity. There are ten departments that The Council gathers: General Affairs; Foreign Affairs; Economic and Financial Affairs; Justice and Internal Affairs; Employment, Social Policy, Health and Consumer Affairs; Competitiveness; Transport, Telecommunications and Energy; Agriculture and Fisheries; Environment; Education, Youth and Culture. Representative Ministers are brought together to attend Council meetings, depending on their relevance to the matters at hand, to hear the prepared decisions from the Committee of Permanent Representatives of the EU countries (COREPER). The Council bases its legally binding decisions, jointly with the European Parliament, on proposals put forward by the European Commission. These decisions are processed using the ordinary legislative procedure of the EU. The Council's decisions can take a simple majority, qualified majority or unanimity voting, depending upon the subject.

See the "Rules of Procedure" of The Council: <u>http://tinyw.in/q0tj</u> ...

3. <u>The European Commission</u>²⁰

Established in 1957, the European Commission (EC) oversees and formulates proposals for EU laws, executes the EU budget, and manages funding for programs all the while remaining independent from all national governments. The Commission is comprised of specific departments and services that can be held accountable to the European Parliament.

See the "Rules of Procedure" of the EC at: <u>https://bit.ly/2YenCU8</u>...

4. <u>The Court of Justice of the European Union (CJEU)</u>²¹

- Union. Retrieved from https://eur-lex.europa.eu/legalcontent/EN/TXT/?uri=LEGISSUM:114576
- ²⁰ EU Publications Office. (2017). Rules of procedure of the European Commission.

Retrieved from https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=LEGISSUM:o10004

²¹ Court of Justice of the European Union (CURIA). (n.d.). Procedure. Retrieved from

¹⁹ EU Publications Office. (2015). Rules of procedure of the Council of the European

CURIA website: https://curia.europa.eu/jcms/jcms/Jo2_7031/en/

Established in 1952, the overarching function of the Court of Justice of the European Union is to ensure the uniform interpretation and respect from EU countries and institutions with regard to EU Law. The CJEU is comprised of two courts:

- 1. The General Court has the jurisdiction to hear motions against EU institutions brought forward by both EU citizens and countries. It has specific jurisdiction to hear and provide rulings in cases between EU Institutions and their civil servants (For more information on the General Court, see <u>https://bit.ly/2YfZVuK</u>).
- 2. The Court of Justice has the primary function to deliver preliminary rulings. It hears some motions against EU institutions brought forward by EU countries and hears appeals from the General Court (For more information on the Court of Justice, see https://bit.ly/2Y98Sps).

In the section *Sweden's Legal System*, there will be further discussion of the legal relationship between the CJEU in the Swedish legal system, along with its implications regarding the Independent Living Institute.

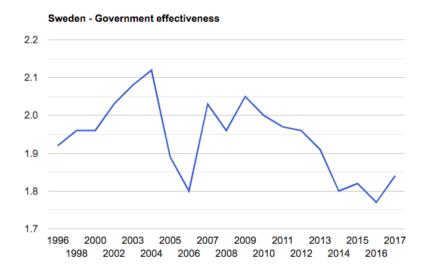
For more information on the rules of procedure for the CJEU, see https://bit.ly/2Yae1xq...

Alterations to the political landscape in Sweden resulting from changes in the composition of political parties, membership in the European Union and other influential factors, has led to a critique that the Swedish government has become less effective in more recent years as a general governing body. The World Bank's index measuring government effectiveness on a scale for -2.5 (weak) and 2.5 (strong) reveals significant fluctuations in government effectiveness since1996. The graph in Figure 1.1 represents government effectives indicated by perceptions of the quality of public services, the quality of the civil service and the degree of its independence from political pressures, the quality of policy formulation and implementation, and the credibility of the government's commitment to such policies. The index reveals a downward trend beginning in 2004.²²

Figure 1.1: Government Effectiveness Index of Sweden from 1996 to 2017

 $^{^{22}}$ Sweden Political stability - data, chart. (n.d.). Retrieved from TheGlobalEconomy.com

website: https://www.theglobaleconomy.com/Sweden/wb_political_stability/



Significant political events occurring in the 1990's and early 2000's that impacted the lives of disabled people may partially account for the positive correlation in perception of government effectiveness from 1996 to 2004 in Figure 1.1. In 1994, Swedish reform for disabled people resulted in the adoption of a law in 1993 for support and service for certain disabled peoples (LSS).²³ Six years later in 2000, a paradigm shift -from "patient" to "citizen"- occurred in disability policy that was driven by the adoption of the Swedish disability action plan.²⁴ Over the past 10 years however, recent changes to Swedish politics have seen a backlash towards the government in response to a series of cuts in personal assistance. It appears that current politicians have limited knowledge or understanding of the impact that substantial changes to Sweden's disability policy have on people's lives. These political actions present challenges for the Independent Living movement in Sweden and for disability advocates.²⁵

The relationship between human rights advocates and political systems is evident in interactions between the Independent Living Institute and politics in Sweden. ILI's work on behalf of people living with disabilities requires a stable political system. If fluctuations in perceptions of government effectiveness exist, as demonstrated in Figure 1.1, the advocacy work of the Independent Living Institute may be threatened. Assuming that declining perceptions of government effectiveness may also represent a loss of trust and increase of instability in government, the strength of ILI's advocacy work could be tested. If ILI's work can gain the proper social and political support to be incorporated into policy, it may assist in

Personal assistance in Sweden. Retrieved from Independent Living Institute website: https://www.independentliving.org/docs7/Independent-Living-movement-paved-way.html

²⁵ Commentary formulated from: J. Bolling, personal correspondence, May 16, 2019

²³ Karnov Group. (1993). Law (1993: 387) on support and service to certain disabled people (LSS). Retrieved from Karnov Group website: <u>https://open.karnovgroup.se/socialratt/lss</u>

²⁴ Ratzka, A. (2012). The Independent Living movement paved the way: Origins of

recuperating the perception of government effectiveness when it comes to disability issues. However, if ILI does not receive the required social and political support, some of its efforts may become lost due to political instability.²⁶

3.2 Levels of Government and the Division of Functions

Sweden has three levels of government: National, regional, and local. Additionally, there is a European level of government that has increasing influence over Swedish State governments. The Government is comprised of official offices representing a number of ministries and about 400 central government agencies and public administrations.²⁷

The national level of government is mainly centered on the central Government, or Regeringen, and the parliament, or Riksdag. The Regeringen is comprised of Government Offices and about 220 other Government agencies. Its function is to enforce decisions of the Riksdag, and initiates new laws and amendments to existing laws. The Riksdag is the highest decision-making assembly in Sweden, the Riksdag is tasked with four main objectives:²⁸

- 1. **The law making function** of the Riksdag begins with a proposal for the creation of a law or an amendment to an existing law in the form of a Government Bill or a motion put forward by one or several members of the Riksdag. All legislative proposals will pass through one committee before being voted on in the Riksdag. A majority of votes is required in order for the legislation to be sent to the Government to become law.
- 2. **Budget determination** for the central government occurs after the Government has submitted proposals in the Budget Bill as to how the money at the disposal of the central government sector should be used. A decision from the Riksdag will be formed and delivered to the Government. The central Government is then entirely responsible for the budget.
- 3. **Examining Government operations** is done in several forms. The Committee on The Constitution ensures the compliance of the Government with existing regulations. The Swedish National Audit Office examines how the central Government utilizes the budget. If confidence is lost in a Minister or the Prime Minister, the Riksdag can choose to make a declaration of no confidence and another election will be held.

²⁶ Commentary formulated from: J. Bolling, personal correspondence, May 16, 2019

²⁷ Government Offices of Sweden. (2019). The Swedish model of government

administration. Retrieved from Regeringskansliet website:

https://www.government.se/how-sweden-is-governed/the-swedish-model-of-

government-administration/

²⁸ The following information in points 1 to 4 is from:

Riksdagsförvaltningen. (2018). What does the Riksdag do? Retrieved from

http://www.riksdagen.se/en/how-the-riksdag-works/what-does-the-

riksdag-do/

4. **EU-related matters** have significant influence on the National Government. As a EU member, Sweden must be represented in EU institutions. The Riksdag is tasked with directing the Government on the political stance that they should take in the EU. The discussions of EU issues occur in the Chamber of the Riksdag, the parliamentary committees and the Committee on EU Affairs. In turn, the legislation passed in both the Riksdag and EU is legally binding to Sweden.

Sweden is divided into 21 counties that comprise the regional level of government. There are two main functions of the regional government that undertake the tasks: the county councils and the county administrative boards. The county councils are comprised of officials elected by the people of the county. The county administrative boards are government bodies that operate within each county.²⁹

The local level of government has 290 municipalities. Each municipality has a municipal council comprised of an elected assembly of individuals that deliberate on municipal matters. The division of tasks between the national and local level governments has changed over the years. The current legislation that discusses the functions, organization and powers of municipalities is the 1992 Swedish Local Government Act. The *Act* also contains rules for elected representatives, municipal councils, executive boards and committees.³⁰

The governing piece of legislation for all three levels of government is the Swedish Constitution. The Constitution is made up of four fundamental laws that define how the country shall be governed.³¹ These laws are:

1. The Instrument of Government

The Instrument of Government contains the basic principles of the formation of Sweden's government. Its adoption in 1974 created a significant reduction in monarchial powers.

2. The Act of Succession

While the Instrument of Government states that a King or Queen shall be the head of state, the Act of Succession of 1810 regulates who is to inherit the throne. Only a male could inherit the throne until 1979 when the Riksdag decided that a woman could also inherit the throne.

3. The Freedom of the Press Act

The most recent Freedom of the Press Act was adopted in 1949. This Act allows for the "right to disseminate information in printed form but with accountability before the law." Further, the Act allows for the citizens the "right to study public documents, the principle of public access to official documents."

²⁹ Supra note 27.

³⁰ Ibid.

³¹ Sveriges Riksdag. (2016). The Constitution of Sweden. *The Fundamental Laws and*

the Riksdag Act. Stockholm: Sveriges Riksdag, Retrieved from

https://www.riksdagen.se/globalassets/07.-dokument--lagar/the-constitution-of-sweden-160628.pdf

4. The Fundamental Law on Freedom of Expression

Adopted in 1991, this Law contains provisions similar to those in The Freedom of the Press Act regarding free dissemination of information and the prohibition of censorship including newer sources of media such as TV, radio, films and CD-ROM discs.

See the Swedish Constitution at: <u>https://www.riksdagen.se/globalassets/07.-dokument--lagar/the-constitution-of-sweden-160628.pdf</u>

An alternate political dimension that has overarching influence on Sweden is the EU level of government. Along with Sweden's membership to the EU in 1995 came political and legal obligations. Sweden is required to provide an elected individual to represent the country at the EU level of government. They also became covered by the EU 'acquis communautaire,' meaning that the laws jointly enacted in the EU will take precedence over Sweden and other member's national laws.³²

The Independent Living Institute (ILI) is aware of the impact and importance of EU decisions to its work and for the field of disability. Therefore, ILI remains an active member of the European Network on Independent Living (ENIL) in order to remain current with elements of the EU agenda that affect the Independent Living movement in Sweden (J. Bolling, personal correspondence, May 16, 2019).

3.3 History of Swedish Elections: A Brief Analysis³³

In the past century, Sweden has experienced different trends in governmental power. From 1932 to 1976, the Social Democrats were in power. A coalition government consisting of the Center Party, the Moderate Party and the Liberals defeated the Social Democrats in the 1976 election. The Social Democrats regained power in 1982 and formed a minority government until 1991 when they lost the election to a new non-Socialist coalition consisting of the Moderate Party, Liberals, Centre Party and Christian Democrats. The Social Democrats then won the next election in 1994 and held their final long stretch as the government in power until 2006. After 2006, there have been a variety of different coalition governments in power.

When analyzing the history of Sweden's governments in power, it is evident that there is a longstanding presence of The Social Democrats. It appears that The Social Democratic party's socialist ideologies have been historically engrained in Swedish society. This partly explains the persistence of current political beliefs leaning towards the left on the left-right political spectrum.

In order to defeat or remove the Social Democrats from power, coalitions often form. In the past four elections, coalitions have formed to stand as the government in power. This may also point to a collaborative nature in Swedish politics where parties must agree and come together regarding political aspirations to gain political power. In tis regard, there is a strong sense of connectivity amongst some of the smaller and newer political parties because

³² Supra note 27.

³³ All of the information in section 3.3 is from:

The Swedish System of Government. (2018). Retrieved from Sweden.se website:

https://sweden.se/society/the-swedish-system-of-government/

of a common understanding that partnership may be the only way to achieve their political aspirations.

While there has been a strong existence of socialist ideology in Swedish politics, there may be a collective initiative to develop a more collaborative and versatile series of governments in power to be able to exact effective policies and legislation that appeal to the increasing variety of political and social views amongst Swedish people.

3.4 Electoral System & Political Parties

Sweden has a democratic proportional representation electoral system. Basically, this means that the percentage of votes that a party receives in the election is the percentage of seats that they will receive in the Riksdag (Swedish Parliament). In order to gain seats in the Riksdag, a party must meet the minimum cut-off of four percent of total votes. There are 349 seats in the Riksdag, that are divided into 310 fixed constituency seats and 39 adjustment seats. On one hand, the constituency seats are based on the number of citizens who are eligible to vote in a constituency. The Election Authority will allocate these fixed seats for all 29 constituencies using the adjusted odd numbers method. On the other hand, the adjustment seats are distributed to the respective parties proportional to the percentage of votes won as if the entire country was one large constituency. With regard to which candidates are awarded a seat in the Riksdag, if five percent of voters in a constituency choose the same candidate, this candidate will automatically receive a seat. If there is more than one name being voted for leading up to the five percent cut-off, seats will be allocated according to the set party list.³⁴

For more information on elections to the Riksdag, see https://bit.ly/2H996r9 ...

As briefly discussed in the preceding section, *Recent Changes to the Swedish Political Landscape*, there are currently eight political parties in Sweden:³⁵

1. **The Social Democrats (SAP)**, founded in 1889, is the socialist party in Sweden that is committed to creating an egalitarian society; it developed a welfare state system following the Great Depression in the 1930's. The SAP was split in 1917 to create the second traditional political party, The Left Party.

For more information on SAP see: https://www.socialdemokraterna.se/

2. **The Left Party**, founded in 1917 and formerly a communist party, now identifies as a socialist and feminist party grounded in an ecological ideology. They claim to strive for the creation of a "society that works for everyone and not just a few." They value the environment, democracy, equality and solidarity towards the promotion of a fair and ecologically sustainable society.

https://www.riksdagen.se/en/how-the-riksdag-works/democracy/elections-to-the-riksdag/

³⁴ All of the information in this paragraph is from:

Sveriges Riksdag. (2019). Elections to the Riksdag. Retrieved from

³⁵ All of the information for the following political parties (1 - 8) is from:

Political parties in Sweden. (2017). Retrieved from sweden.se website:

https://sweden.se/society/political-parties-in-sweden/

For more information on The Left Party see: <u>https://www.vansterpartiet.se/</u>

3. **The Moderate Party** founded in 1904, began as a conservative and nationalist party. It has more recently transformed into a conservative party that promotes liberal ideas. The Moderate Party focuses on developing a society in which "rights, obligations and opportunity is[are] equal to all."

For more information on The Moderate Party see: https://moderaterna.se/

4. **The Center Party**, founded in 1913 and originally called The Farmers' League, is a liberal and agricultural party that focuses on national economy, the environment and integration. Their central belief is that power to the people is key for individuals have the right and ability to shape their own future.

For more information on The Center Party see: <u>https://www.centerpartiet.se/</u>

5. **The Liberals** were founded in 1934 under the former title The People's Party; it was re-named in 2015 following a series of internal changes. This party claims to have a central political standing with its ideology grounded in liberalism based on respect for the individual. The Liberals stand by a definition of liberalism that says freedom is a movement that brings everyone together to help within society and fund welfare as a collective.

For more information on The Liberals see: <u>https://www.liberalerna.se/</u>

6. The **Sweden Democrats** were founded in 1988 as a social conservative party based on nationalism. They attempt to protect the Swedish 'national identity' through more stringent immigration policies that sustain the Swedish welfare State.

For more information on Sweden Democrats see: https://sd.se/

7. The **Christian Democrats**, founded in 1964, focuses on creating a democracy based on Christian human vision and values. The party focuses on putting human dignity first and prioritizing what they see as necessary to building a society that holds together. They concern themselves with four main issues: improving elder care, the freedom to select childcare options, simplifying regulations for companies, and combatting unemployment and promoting growth by lowering taxes.

For more information on Christian Democrats see: https://kristdemokraterna.se/

8. **The Green Party**, founded in 1981, focuses on addressing climate change and protecting the environment, fighting nuclear power, and promoting European integration. As a feminist party, their two spokespersons always consist of one man and one woman.

For more information on The Green Party see: <u>https://www.mp.se/</u>

3.5 Proposal for a New Strategic Disability Policy³⁶

Following Sweden's ratification of the UN Convention on the Rights of Persons with Disabilities in 2008, there was a five-year term, from 2011 to 2016, for the use of strategic

³⁶ All of the information in 3.5 is from:

Proposals on a new structure for the Swedish disability policy. (2017). Retrieved

implementation methods for disability. Beginning in 2017, the Swedish government tasked the Swedish Agency for Participation (MFD) with evaluating former disability policies and developing a proposal for implementing new strategic measures to develop more effective, sustainable and clearer disability policy. This strategy does not yet have a set end date for it is currently being discussed. The evaluation of the 2011 to 2016 strategy displayed development in areas of physical accessibility and the labour market became stagnant or has advanced slowly. Other dimensions of the evaluation studied the situation of disabled refugees and asylum seekers, as well as a gender analysis of this policy.

The importance of this new strategy is for the sustainable development of society and for Sweden to meet its international requirements respective of the UN's sustainable development goals Agenda by 2030. The new strategy will emphasize a necessity for rigorous policy integration in all societal areas. Therefore, it must be stable, flexible and systematic in nature. The MFD has proposed eleven prioritized areas to be targeted as a basis for the strategy:

- 1. Work and make a living
- 2. Education
- 3. Transport
- 4. The physical environment and urban planning
- 5. IT, innovation and technology development
- 6. Health
- 7. Social welfare
- 8. Culture, sports and recreation
- 9. Consumer
- 10. Democracy
- 11. Judicial system

Each of these areas will have effect targets and results objectives. The effect targets will focus on the outcomes of disability policy regarding equality and participation. Conversely, the results objectives deal with the conditions for disability policy regarding equality and participation. Additionally, MFD clarifies methods and tools for developing each specific area.

On May 8, 2019, the Ministry of Social Affairs tasked the steering committee to review the governance and follow-up with the government's disability policy proposal in 2017 (SOU 2019: 23). According to the new proposal, the goals within certain prioritized social areas shall be linked to the new national policy goal and to the realization of rights.³⁷

 $from\ http://www.mfd.se/other-languages/english/swedish-disability-policy/proposals-on-a-new-structure-for-the-swedish-disability-policy/$

³⁷ Regeringskansliet. (2019). Steering force in disability policy. Retrieved from Regeringskansliet website:

https://www.regeringen.se/rattsliga-dokument/statens-offentliga-utredningar/2019/05/sou-201923/

4) Sweden's Legal System

4.1 Legislative process in Sweden³⁸

The legislative process in Sweden has six stages:

1. Initiative

While the Government puts forward the majority of legislative proposals to the Riksdag, there are some cases in which private entities and special interests groups are able to bring forward legislative proposals through members of parliament.

2. The inquiry stage

Before the Government can create a proposal for legislation, there must be an official analysis and evaluation of the current matter in question. Officials from the ministry, a commission of inquiry or a one-person committee carries out this process. These inquiry bodies work independently from the government and formulate recommendations that are published in reports to the government website.

3. The referral process

The report from the inquiry stage is distributed to the relevant referral bodies for further assessment. Referral bodies are internal entities that may be central government agencies, special interest groups, local government authorities, or anybody that may be affected by the proposal. The purpose of this stage is to give feedback and to help the Government gauge the support it is likely to receive for the particular proposal.

4. Government bill

After these preliminary stages, the Ministry will draft the bill that will be submitted to the Riksdag. If the bill will have significant effects on individuals or the welfare of the public, it must first go through the Council on Legislation that will ensure that the proposed legislation does not conflict with existing legislation.

³⁸ All of the information in 4.1 is from:

Government Offices of Sweden. (2015). Swedish legislation - how laws are made.

Retrieved from Regeringskansliet website: https://www.government.se/how-sweden-is-governed/swedish-legislation---how-laws-are-made/

5. The parliamentary process

The Riksdag approves all of the new or amended legislation. A bill is dealt with by one of the parliamentary committees. Any of the Riksdag members can propose a counter-proposa or a motion to any bill put forward by the Government. If the Riksdag chooses to accept the motion instead of the Government proposed bill, the provisions of the motion become binding. Once the parliamentary committee completes its deliberations, a report is formed and sent to the chamber of the Riksdag to receive collective approval. If the Riksdag chooses to adopt the bill, it becomes law.

6. Promulgation

The law is then formally promulgated once it has successfully passed through the Riksdag. This new or amended law is published in the Swedish Code of Statutes.

Since the establishment of the Independent Living Institute and rise of the Independent Living Movement in Sweden, most of ILI's work concerns the "initiative" stage of the legislative process. The legislation proposed by ILI perceives issues through a lens that recognizes the importance of the independent living philosophy and interjects these progressive ideas into the legislation where necessary. Currently, ILI has been enabling individuals in the community to participate in free consultations in which they can deliver their own ideas regarding public inquiry and government proposals. The purpose of gathering input is to understand common perceptions towards proposed or current legislation in order to create change towards having legislation that illustrates an independent living and human rights perspective (O. Linder, personal correspondence, May 15, 2019).

4.2 Application of EU laws in Sweden³⁹

On January 1, 1995 Sweden became a member of the European Union resulting from their referendum in 1994. While membership means influence and involvement in the EU's work, it comes with legal obligations. There are two types of EU law that place legal obligations on EU states like Sweden. First, regulations and decisions are overarching laws remaining at the EU level and become automatically legally binding the date that they come into force. Their implementation is monitored and enforced by national authorities. Second, directives coming from the EU level must be incorporated into national legislation. Directives contain specific deadlines for which national governments must incorporate their contents into national legislation and report back to the Commission. The EU Commission provides

³⁹ All of the information in 4.2 is from:

Applying EU law. (n.d.). Retrieved from European Commission - European

Commission website: https://ec.europa.eu/info/law/law-making-process/applying-eu-law_en

implementation services that assist member States when incorporating EU laws into their national legislation.

The EU Commission is the enforcement mechanism for all forms of EU laws to ensure that member States fully incorporate a directive into its national laws by a set deadline, and to ensure the correct application of EU law. If a member State fails to abide by the implementation requirements, the Commission may launch a formal infringement procedure against the country in question. If the country in question continues to fail to abide by EU requirements, the Commission can bring the matter to the European Court of Justice.

While the Swedish government, in general, will sufficiently fulfill implementation requirements of EU law, they must still be monitored by external sources. For matters that affect the work being done at ILI, the initiative has been taken to evaluate and monitor the implementation of certain EU laws. If the EU laws are not being implemented correctly, it is the decision of ILI to notice and act on the information.

For more information about applying EU law, see <u>https://ec.europa.eu/info/law/law-making-process/applying-eu-law_en</u>

4.3 Relevant Laws and International Conventions Regarding Independent Living

There are a number of Swedish laws, in addition to EU laws, that are relevant to the work being done by ILI. ILI must remain conscious of the level of authority that EU laws have over Swedish law, and that EU laws are equally as legally binding to Sweden as their own laws.⁴⁰ Furthermore, while Sweden has ratified the UN Conventions, they are not legally binding in Sweden.

Sweden's Laws and Acts Concerning Disability Issues:

- Act on the Recognition and Enforcement of Nordic Judgements in the Field of Private Law (1977: 595) (<u>https://open.karnovgroup.se/utsokningsratt/SFS1977-0595</u>)
- The Work Environment Act (1977: 1166) (<u>https://open.karnovgroup.se/arbetsratt/arbetsmiljolagen</u>)
- Health and Medical Care Act (1982: 763) (<u>https://open.karnovgroup.se/halso-och-sjukvard/SFS1982-0763</u>)
- The Compulsory Mental Care Act (1991: 1129) (<u>https://open.karnovgroup.se/halso-och-sjukvard/lpt</u>)
- Medical Devices Act (1993: 584) (<u>https://open.karnovgroup.se/halso-och-</u> sjukvard/SFS1993-0584)

⁴⁰ Cuyvers, A. (2017). The Scope, Nature and Effect of EU Law. In A. Cuyvers, E.

Ugirashebuja, J. E. Ruhangisa, & T. Ottervanger (Eds.), *East African Community Law* (pp. 161–181). Retrieved from http://www.jstor.org/stable/10.1163/j.ctt1w76vj2.12

- The Medical Devices Ordinance (1993: 876) (https://open.karnovgroup.se/naringsratt/SFS1993-0876)
- Law on support and service to certain disabled peoples (LSS) (1993: 387) (<u>https://open.karnovgroup.se/socialratt/lss</u>)
- Social Services Act (2001: 453) (https://open.karnovgroup.se/socialratt/socialtjanstlagen)
- Social Insurance Bar (2010: 110)(<u>https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/socialforsakringsbalk-2010110_sfs-2010-110</u>) (refer to AVD. D Special Benefits at Disabilities)
- The Patient Act (2014: 821) (<u>https://open.karnovgroup.se/halso-och-</u> sjukvard/patientlag)

European Union:

- Regulation No. 1107/2006 concerning the rights of disabled persons and persons with reduced mobility when travelling by air (<u>https://eur-lex.europa.eu/legal-content/EN/TXT/?gid=1557829012419&uri=CELEX:32006R1107</u>)
- Directive 2000/78/EC against discrimination at work on grounds of religion or belief, disability, age or sexual orientation. (<u>https://eur-lex.europa.eu/legal-</u> <u>content/EN/TXT/?uri=celex%3A32000L0078</u>)

United Nations:

• Convention on the Rights of Persons with Disabilities (UNCRPD) (https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

5) The Council of Europe and UN as Influencing Bodies

5.1 European Court of Human Rights vs. UN Committee on the Rights Persons with Disabilities

If legal disputes involving disabled persons cannot be resolved on a national level, they can be brought to the international level to seek resolution. There are two main international legal institutions where unresolved matters can be heard with regard to disability rights (O. Linder, personal correspondence, May 15, 2019):

1. <u>The European Court of Human Rights (ECtHR)⁴¹</u>

⁴¹ The information in this paragraph is from:

European Court of Human Rights. (n.d.). International Justice Resource Center.

Retrieved from International Justice Resource Center website:

Created with the guidance of the Council of Europe, the European Court of Human Rights is based in Strasbourg, France. It began its operations in 1959. The Court has jurisdiction to make legally binding decisions on applications put forward by individuals and States concerning the European Convention on Human Rights. While the individual putting forward the application is not required to be a State party, the alleged violations of the Convention are required to have been committed by a State party, and must directly and significantly affect the applicant.

For more information regarding the structure and proceedings of the ECHR, see https://ijrcenter.org/european-court-of-human-rights/

2. The UN Committee on the Rights of Persons with Disabilities (UNComRPD)⁴²

On December 13, 2006, the UN General Assembly adopted a new international human rights treaty called the Convention on the Rights of Persons with Disabilities (CRPD. It came into force on May 3, 2008. The Convention currently has 147 signatories and was ratified by the European Union. In order to monitor the implementation of the CRPD, a body of 18 independent and elected experts sit on the UN Committee on the Rights of Persons with Disabilities. All States party to the CRPD must submit annual reports discussing their implementation of the CRPD, allows for the receipt and examination of individual complaints, and the undertaking of evidence from inquiries that demonstrate severe violations of the CRPD. The Committee does not make legally binding judgments; they formulate general comments with the purpose of helping States improve their implementation techniques with respect to the CRPD.

For more information regarding the all Committee guidelines, see https://www.ohchr.org/EN/HRBodies/CRPD/Pages/Guidelines.aspx

ILI evaluates the advantages and disadvantages of taking matters to the ECtHR and the UNComRPD. On a case-by-case basis, the ILI assesses these pros and cons when bringing matters before these international bodies:⁴³

https://ijrcenter.org/european-court-of-human-rights/

⁴² The information in this paragraph is from:

OHCHR (n.d.). CRPD Guidelines. Retrieved from

https://www.un.org/en/ga/search/view_doc.asp?symbol=CRPD/C/1/Rev.1

⁴³ The information in the table is from: O. Linder, personal correspondence, May 15, 2019

	ECtHR	UNCmRPD
PRO's	 Legally binding judgments Comprised of a large collection of well-developed jurisprudence If violation of right's is found, compensation can be awarded 	 All human rights can be tried Strong perspective in favor of disability right's across the adjudicating panel
CON's	 Lengthy and complex proceedings The court is reluctant to hearing economic, social and cultural rights for it is not entirely within its jurisdiction 	 Delivers non-binding recommendations Less-developed collection of jurisprudence Lower authoritative status in comparison to the ECtHR

5.2 Office of the High Commissioner for Human Rights: Relevant Conventions

UN Office of the High Commissioner for Human Rights (OHCHR)⁴⁴

Founded on December 20, 1993, the OHCHR became the primary UN entity that focuses on human rights. There has always been a general focus on human rights since the establishment of the UN in 1945, although there has not been a specific office mandated to promote and protect human rights in the lives of all people. The main function of the OHCHR in compliance with its mandate, is to provide "a forum for identifying, highlighting and developing responses to today's human rights challenges, and act as the principal focal point of human rights research, education, public information, and advocacy activities in the United Nations system." The OHCHR achieves its mandate by partnering with Governments, national human rights institutions, and individuals and groups within civil society. While monitoring implementation techniques for international human rights standards, the OHCHR also works on the ground in communities to ensure proper implementation of these standards in practice.

For more information on the history, mandate, and mission statement of the OHCHR, see https://www.ohchr.org/EN/AboutUs/Pages/WhoWeAre.aspx

⁴⁴ The information in this paragraph is from:

OHCHR (n.d.). Who we are. Retrieved from

https://www.ohchr.org/EN/AboutUs/Pages/WhoWeAre.aspx

UN Convention on the Rights of Persons with Disabilities (CRPD)⁴⁵

The CRPD was adopted by the UN General Assembly on December 13, 2006; it opened to signatures on March 30, 2007 and came into force on May 3, 2008. Currently, there are 177 ratifications/accessories (162 signatories) of the CRPD and 92 ratifications/accessories (92 signatories) to the Optional Protocol. The CRPD is the first international treaty that sets a minimum standard for rights for persons with disability. Each of the Convention's 50 articles contributes to its overall purpose "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." The Optional Protocol came into force at the same time as the CRPD. Its function is to allow for "[the reception] and [consideration of] communications from or on behalf of individuals or groups of individuals subject to its jurisdiction who claim to be victims of a violation by that State Party of the provisions of the Convention."

For the full CRPD and its Optional Protocol, see https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

UN Convention on the Rights of the Child (CRC)⁴⁶

The Convention on the Rights of the Child was adopted and opened for signature, ratification, and accession by the General Assembly resolution on November 20, 1989; it came into force on September 2, 1990. The CRC consists of 54 articles that present an array of different rights that every child is entitled to. It is the duty of States parties to "…respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind…" and to "…take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members." The primary Article that connects the CRC with the work being done at ILI is Article 2.1, stating that the rights set forth in the Convention apply to all children, including those with disabilities. The CRC is especially relevant to the Swedish legal system. On March 15, 2018, the Government adopted a bill that made the UN Convention on the Rights of the Child Swedish law. This created a distinct role

Optional Protocol. Retrieved from

https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

https://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf

⁴⁵ The information in this paragraph is from:

United Nations (2006). Convention on the Rights of Persons with Disabilities and

⁴⁶ The information in this paragraph is from:

United Nations. (1989). Convention on the Rights of the Child. Retrieved from

for the child as a legal entity that now has their own set of legal rights under Swedish legislation.

For the full CRC, see https://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf

Like any other legal system, laws in theory may differ from the interpretation and application of laws. In Sweden, judges have the ability to interpret the laws at their own discretion that may sometimes result in unexpected and undesirable results. This adds to the collection of jurisprudence in Sweden that can be referenced as precedent in future cases of a similar nature. This poses issues for the legal team at ILI and other non-governmental organizations who use the law to advocate for disability rights in Sweden since precedent has a fairly high status in Sweden. Further, the practical application of laws, now in the form of legal precedent, may deviate from the legislators' intended purpose for the law. Therefore, the legal battles fought by ILI and others regarding disability rights must consider how present legal rulings will shape how legal battles will be fought in the future.⁴⁷

⁴⁷ The information in this paragraph is from: O. Linder, personal correspondence, May 15, 2019

Bibliography

- About Assistanskoll. (n.d.) Retrieved from Assistanskoll website: https://assistanskoll.se/om-assistanskoll.html
- About. (n.d.). Retrieved from Ed Roberts Campus website: https://www.edrobertscampus.org/about/
- Amadeo, K. (2019). How Europe Became an Economic Powerhouse. Retrieved from The Balance website: https://www.thebalance.com/what-is-the-european-union-how-it-works-and-history-306356
- Applying EU law. (n.d.). Retrieved from European Commission European Commission website: https://ec.europa.eu/info/law/law-making-process/applying-eu-law_en
- Bruce, A. (2014). Which Entitlements and for Whom?: The Convention on the Rights of Persons with Disabilities and its Ideological Antecedents. Sweden: Media-Tryck.
- Court of Justice of the European Union (CURIA). (n.d.). Procedure. Retrieved from CURIA website: https://curia.europa.eu/jcms/jcms/Jo2_7031/en/
- Cuyvers, A. (2017). General Principles of EU Law. In A. Cuyvers, E. Ugirashebuja, J. E. Ruhangisa, & T. Ottervanger (Eds.), *East African Community Law* (pp. 217–228). Retrieved from http://www.jstor.org/stable/10.1163/j.ctt1w76vj2.16
- Cuyvers, A. (2017). The Institutional Framework of the EU. In A. Cuyvers, E.
 Ugirashebuja, J. E. Ruhangisa, & T. Ottervanger (Eds.), *East African Community Law* (pp. 79–102). Retrieved from http://www.jstor.org/stable/10.1163/j.ctt1w76vj2.8

Cuyvers, A. (2017). The Scope, Nature and Effect of EU Law. In A. Cuyvers, E.

Ugirashebuja, J. E. Ruhangisa, & T. Ottervanger (Eds.), *East African Community Law* (pp. 161–181). Retrieved from http://www.jstor.org/stable/10.1163/j.ctt1w76vj2.12

Ed Roberts. (2019) Retrieved from Encyclopedia Britannica website: https://www.britannica.com/biography/Ed-Roberts

Elgenius, G., & Wennerhag, M. (2018). The changing political landscape in Sweden. Sociologisk Forskning, 139-154.

ENIL, the European Network on Independent Living: Documents. (1999). Retrieved from https://www.independentliving.org/docs2/enildocs.html#anchor862229

EU Publications Office. (2015). Rules of procedure of the Council of the European Union. Retrieved from https://eurlex.europa.eu/legalcontent/EN/TXT/?uri=LEGISSUM:114576

EU Publications Office. (2017). Rules of procedure of the European Commission.

Retrieved from https://eur-lex.europa.eu/legalcontent/EN/TXT/?uri=LEGISSUM:o10004

EU Publications Office (2017). Treaty establishing the European Coal and Steel Community, ECSC Treaty. Retrieved from https://eur-lex.europa.eu/legal-content/EN/ALL/?uri=LEGISSUM:xy0022

European Commission. (February 12, 2015). Directive of the European Parliament

and of the Council on the approximation of the laws, regulations and administrative provisions of the Member States as regards the accessibility requirements for products and services. Brussels: European Parliament and of the Council. Retrieved from https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:52015PC0615&from=EN

European Court of Human Rights. (n.d.). International Justice Resource Center.

Retrieved from International Justice Resource Center website:

https://ijrcenter.org/european-court-of-human-rights/

European Parliament Timeline. (n.d.). Retrieved from European Parliament Timeline website: http://www.europarl.europa.eu/about-parliament/en/in-the-past

Government Offices of Sweden. (2015). Swedish legislation - how laws are made.

Retrieved from Regeringskansliet website: https://www.government.se/how-swedenis-governed/swedish-legislation---how-laws-are-made/

Government Offices of Sweden. (2019). Convention on the Rights of the Child will

become Swedish law. Retrieved from Regeringskansliet website:

https://www.government.se/articles/2018/03/new-legislative-proposal-on-the-convention-on-the-rights-of-the-child/

Government Offices of Sweden. (2019). The Swedish model of government administration. Retrieved from Regeringskansliet website: https://www.government.se/how-sweden-is-governed/the-swedish-model-ofgovernment-administration/

Hasler, F. (2003). Philosophy of Independent Living. Retrieved from Independent Living Institute website: https://www.independentliving.org/docs6/hasler2003.html

Independent Living Institute. (2018). Action Plan 2017-2019. Retrieved from Independent Living Institute website: http://independentliving.org

Independent Living Institute (2019). About the Independent Living Institute (ILI).

Retrieved from Independent Living Institute website: https://www.independentliving.org/about.html

Karnov Group. (1993). Law (1993: 387) on support and service to certain disabled people (LSS). Retrieved from Karnov Group website: https://open.karnovgroup.se/socialratt/lss Lindén - Swedish national policy on disability 2016. (2016). Retrieved from https://rm.coe.int/16806b9579

OHCHR (n.d.). CRPD Guidelines. Retrieved from

https://www.ohchr.org/EN/HRBodies/CRPD/Pages/Guidelines.aspx

OHCHR (n.d.). Who we are. Retrieved from

https://www.ohchr.org/EN/AboutUs/Pages/WhoWeAre.aspx

Political parties in Sweden. (2017). Retrieved from sweden.se website:

https://sweden.se/society/political-parties-in-sweden/

Proposals on a new structure for the Swedish disability policy. (2017). Retrieved from

http://www.mfd.se/other-languages/english/swedish-disability-policy/proposals-on-a-new-structure-for-the-swedish-disability-policy/

Ratzka, A. (1992). What is your personal definition of Independent Living?. Retrieved

from Independent Living Institute website: https://www.independentliving.org/toolsforpower/tools11.html

Ratzka, A. (2003). Independent Living in Sweden. Retrieved from Independent Living Institute website: https://www.independentliving.org/docs/Independent_Living_in_Sweden.html#origin s

Ratzka, A. (2012). The Independent Living movement paved the way: Origins of

Personal assistance in Sweden. Retrieved from Independent Living Institute website: https://www.independentliving.org/docs7/Independent-Living-movement-paved-way.html

Regeringskansliet. (2019). Steering force in disability policy. Retrieved from

Regeringskansliet website: https://www.regeringen.se/rattsliga-dokument/statensoffentliga-utredningar/2019/05/sou-201923/

Riksdagsförvaltningen. (2018). What does the Riksdag do? Retrieved from

http://www.riksdagen.se/en/how-the-riksdag-works/what-does-the-riksdag-do/

Shapiro, J. P. (1993). No Pity: People with Disabilities Forging a New Civil Rights Movement. New York, USA: Times Books.

Sveriges Riksdag. (2019). Elections to the Riksdag. Retrieved from

https://www.riksdagen.se/en/how-the-riksdag-works/democracy/elections-to-the-riksdag/

Sveriges Riksdag. (2016). The Constitution of Sweden. *The Fundamental Laws and the Riksdag Act.* Stockholm: Sveriges Riksdag, Retrieved from

https://www.riksdagen.se/globalassets/07.-dokument--lagar/the-constitution-of-sweden-160628.pdf

Sweden - Government and society. (2019). Retrieved from Encyclopedia Britannica website: https://www.britannica.com/place/Sweden

Sweden - Political process. (2019). Retrieved from Encyclopedia Britannica website: https://www.britannica.com/place/Sweden

Sweden Political stability - data, chart. (n.d.). Retrieved from TheGlobalEconomy.com website: https://www.theglobaleconomy.com/Sweden/wb_political_stability/

The Law as a Tool. (n.d.). Retrieved from Independent Living Institute website: https://www.independentliving.org/taxonomy/term/48

The Swedish electoral system. (2018). Retrieved from Valmyndigheten website: https://www.val.se/servicelankar/other-languages/english-engelska/the-swedishelectoral-system.html

The Swedish System of Government. (2018). Retrieved from Sweden.se website: https://sweden.se/society/the-swedish-system-of-government/ United Nations Department of Economics and Social Affairs - Disability. (n.d.). Resources. Retrieved from United Nations website: https://www.un.org/development/desa/disabilities/resources.html

United Nations. (1989). Convention on the Rights of the Child. Retrieved from https://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf

United Nations (2006). Convention on the Rights of Persons with Disabilities and Optional Protocol. Retrieved from https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf