

Annual Report 2020

Independent Living Institute (ILI) works to promote opportunities for individuals with disabilities for more personal and political power, self-determination, full participation and equality through information, education, lobby and project activities. During 2020, ILI carried out several projects to reach its goals and visions which are described in this document. All the projects have their own webpage, Facebook-page, and publish newsletters.

The structure of this annual report is as follows:

1) project activities, 2) other on-going activities and information on the institute including a list of events, news articles, consultation responses as well as materials produced during the year. There are also lists of the office staff, board members, and funding received.

Project Activities

Disabled Refugees Welcome (DRW)

<u>Disabled Refugees Welcome</u> is an integration project carried out since 2017 with funding from the Swedish Inheritance fund (*Allmänna Arvsfonden*). The project funding ended on the 31st December 2020 with some activity continuing within ILI on a lesser scale with plans for cooperation that builds on DRW's methods and results.

The purpose of DRW has been to develop new methods that improve the conditions of reception and integration of newcomers and migrants with various disabilities. During the project, DRW documented the needs of the target group and developed many activities that, in the future, can become a natural part of the Swedish migration system.

Migrants with disabilities face almost insurmountable obstacles in the form of, for example, lack of accessibility, information and coordination. The consequences are that access to housing, health and medical care, SFI (Swedish language for immigrants) and vocational education, work, culture and leisure is limited. For many people the establishment process stops and the genuine participation in the community is absent. The Swedish goal, where people with disabilities are to benefit from human rights, is falling apart. Instead, DRW's results show that comprehensive measures are needed to achieve mutual integration.

DRW's methodological material: the information handbook "Roads to mutual integration" and the method handbook "Welcome whoever you are", collect DRW's conclusions, the target group's needs, analysis of the situation and measures needed to achieve mutual integration.

In 2020, DRW has been very active. The project has been presented in several cities around Sweden. The method material was produced and published in various formats during the year. 447 people have participated in the project's activities. 30 migrants with disabilities have contacted the project for support / counseling and several who applied for support in previous years have continued to be in contact with the project. In total, more than 80 case studies with the target group of migrants have been carried out, where experience has been utilized in the development of DRW's method material.

The website, social media channels, events and the network have been used to disseminate information about DRW's results. The website had about 5,000 visits, 6 newsletters were sent out containing 59 news articles, interviews, films and event information. At the beginning of 2020, DRW's Facebook page had 458 followers. There was a constant stream of new people seeking DRW's expertise. The project has been interviewed in the media several times.

The project has included a variety of activities in addition to the method development itself, such as peer support, Photovoice, theme days, information dissemination, training, study visits, seminars / webinars, roundtable discussions, case studies / interviews, counseling / accompaniment, trainee and volunteer activities. Participant-driven methods have functioned both as means and goals in the project.

Article 19 as a tool (Artikel 19 som verktyg)

In 2018, the Swedish Inheritance Fund (*Allmänna Arvsfonden*) decided to grant funding for ILI's project Article 19 as a tool for three years. The project officially started on April 1, 2019, which defines the projector's start and end dates. The project is managed through dialogue with an active and competent reference group and the steering group consisting of ILI and the Raoul Wallenberg Institute (RWI).

During the year, the work was based on the three previously established main tracks: 1) raising awareness of rights among rights holders, 2) finding methods to be able to follow up on how well Sweden is complying with its international obligations, and 3) developing legislative proposals for better implementation of the commitments.

Various activities have been carried out with partner municipalities and civil society organizations. This has concerned education, discussion groups on Article 19 and the situation for rights holders, study circles as well as policy development and consultation responses to bills. Information has been developed continuously through articles and posts on the website www.lagensomverktyg.se and in social media. The legal gap analysis has continued and a guide for individual complaints to the UN Committee on the Rights of Persons with Disabilities (CRPD) has in principle been published. The follow-up tool has been in a strong development phase and several discussion groups have continued and some new ones have been established to test the first results from year 1. The counseling has developed and attracted many support applicants; 64 incoming cases have been registered in 2020 with the project and several of these and previous cases have been active through recurring contacts.

The collaboration with RWI has had a very positive synergy effect by establishing a Law Clinic in collaboration between the organizations. ILI and Article 19 as a tool provided tasks for students to work with, which are linked to ILI's strategic work for the implementation of human rights and improved living conditions for people with disabilities. The dialogue with the students, RWI and other important contacts such as Theresia Degener and Elisabet Fura have provided a quality assurance in the student reports.

<u>The website for the project</u> had 25,000 visits from 20,000 people during the year 2020. The website is the same as for the previous project - The law as a tool. Facebook page Article 19 / The law as a tool had 475 followers, the newsletter had 288 subscribers and went out with 9 issues during the year. Seven episodes of the podcast Whose choice? have been published in 2020.

The Disability Discrimination Reporting Service (Anmälningstjänsten)

<u>Anmälningstjänsten</u> helps individuals and organizations to report discrimination cases to the Equality Ombudsman and, where applicable, the respective municipal building committee. The service has been developed and has existed since the late 1990s. During the year, the site had about 8,800 visits from about 8,500 people, slightly lower than in 2019. The service was administered in 2020 through funding from the Swedish Inheritance Fund (*Allmänna Arvsfonden*) via project Article 19 as a tool.

The law as a tool

The Swedish Inheritance Fund project ended in 2019, but operations have continued to some extent even since then. The project worked to increase the disability movement's access to legal expertise in terms of education, defense and further development of work against discrimination of people with disabilities. The purpose was to help ensure that the rights of people with disabilities are better met by working against negative discrimination and structural discrimination with the law as a tool and case law.

In 2020, dialogue continued with prominent figures in the world of anti-discrimination, and ILIs work continues to make an impression even after the project is completed. A couple of examples concern the surveys on the municipalities' handling of reports of easily remedied obstacles, as well as the Equality Ombudsman's lack of supervision of employers' work with active measures against discrimination. In 2020, a state investigation was underway with a focus on active measures and supervision, to which ILI sent material and participated in a hearing on the work. The project Article 19 as a tool has produced a guide for complaints to the Committee on the Rights of Persons with Disabilities (CRPD) based on insights made during the project Law as a tool and the legal process of Rickard Sahlin vs. Sweden in which Disability Rights Defenders Sweden has been a driving force with the Swedish Deaf National Association and the Swedish Deaf Youth Association.

ILI continues to work with the right to access to justice in project Article 19 as a tool, and contacts in the rest of civil society and academia are developed there. Several organizations still refer to ILI for legal advice or to seek legal representation to assist in conducting individuals' legal proceedings as a result of the work done in project The law as a tool.

Disability Rights Defenders (DRD)

Disability Rights Defenders is a network of people and organizations with an interest in rights and law that concern people with disabilities. The overall purpose of the network is access to rights on equal terms with others. The network disseminates and deepens legal expert knowledge about the rights of people with disabilities, disability rights organizations, lawyers and legal education. By mutually sharing legal knowledge, the ability to use the law as a tool is strengthened. We do this by bringing people together in our Facebook group 'Disability Rights Defenders'. In 2020, the Facebook group grew to 2,300 members from over 100 countries. Members share their experiences, methods and advice on how to use the law as a tool. The content of the Facebook group is summarized in newsletters a few times a year.

In collaboration with the European Network on Independent Living (ENIL), DRD held two successful webinars. The <u>first webinar</u>, in May 2020, was about Legal Clinics - a tool for promoting the rights of people with disabilities. The <u>second webinar</u>, in November 2020, was about legal action by pursuing cases concerning the rights of people with disabilities. Both webinars are published on Youtube. The webinars reached approximately 30-40 participants per occasion and were very successful. The rich discussions and the growing number of participants show that there is a great interest in webinars as a method for discussing and disseminating information. In November, a digital "kick-off meeting" was held with the Nordic section of the network. The Disability Rights Defenders network is funded by Bente Skansgård Independent Living Fund.

Compete with usability and accessibility

The project Compete with usability and accessibility - Standardization to reach new markets / increased market shares was a project owned by KTH and carried out together with Begripsam, Ergolab and the Independent Living Institute. The purpose was to investigate how accessibility and usability, as well as the use of standards, contribute to increased competition, as well as what factors that companies and other actors see as guidelines for creating accessible and useful products and services. ILI helped conduct interviews with relevant actors, disseminate a survey and analyze material from a human rights and sustainability perspective. Agenda 2030 and relevant international law are important documents for

understanding the actors' actions. The initial work was completed in 2019, and the project was completed in May 2020.

TRIPS

ILI is participating in an EU project called TRIPS = TRansport Innovation for disabled People needs Satisfaction. The aim of the project is to improve the transport systems for people with disabilities in Europe.

ENIL, the European Independent Living Network, is a partner and ILI is a sub-partner with Stockholm as its project area. It is a three-year project, from February 2020 to January 2023, and there are 7 European cities included in the project: Bologna, Brussels, Cagliari, Lisbon, Sofia, Stockholm and Zagreb.

TRIPS brought together different people in so-called "co-production groups" in each city. In these groups, people with disabilities, transport providers, municipal managers and other people involved in the transport sector work together to find solutions for how transport can be made more accessible.

The DI project - a paper on de-institutionalization

With funding from the Grant Foundation (<u>Bidragsstiftelsen</u>), ILI has been running a project in the fight against institutionalization since November 2020. In the project, a paper will be produced in Swedish and English, entitled "The freedom to decide where you want to live: de-institutionalization".

The publication intends to describe Sweden's process and history of closing institutions. The publication also intends to describe the importance of support measures according to the Law of Support and Services to Some Persons with Disabilities (LSS) and the Independent Living movement's work and development of personal assistance. This work was important for the Swedish reform during the closure of large institutions as the support was regulated/replaced with the LSS reform and with personal assistance. The paper also intends to highlight today's challenges with risks for institution-like solutions and re-institutionalization.

On the International Day of Persons with Disabilities, December 3, 2021, the publication is planned to be presented publicly. Thereafter, translation, dissemination and advocacy work will be carried out, which is aimed at the relevant decision-makers and those responsible for operations.

Independent Living via sign language interpretation in working life and beyond

With funding from the Independent Living Development Foundation (ILU), ILI together with the association Disability Rights Defenders Sweden runs a project on the right of hearing-impaired persons to cash support for sign-language interpretation, which is based on conclusions and recommendations by the UN Committee on the Rights of Persons with Disabilities (CRPD) in the Rickard Sahlin vs. Sweden case. The project period is November 2020 - March 2021.

We see an opportunity in analyzing in particular the UN Committee's recommendation on necessary reforms for equal rights and linking it to the ongoing interpreting services inquiry by highlighting Independent Living aspects on the issue, especially solutions based on the cash benefit principle.

The project will result in a memorandum that contains the necessary analyses and discussions about solutions based on Independent Living principles. The cash benefit principle in relation to sign language interpretation would improve individual self-determination by giving the individual the means to choose who performs the service, when and how it is done. The memorandum shall form a basis for disseminating the conclusions in the analyses and discussions. We see this as an opportunity to develop Independent Living solutions outside the area of personal assistance and in that way give people with disabilities increased personal power, self-determination, full participation and equality.

Monitoring Personal Assistance Services (Assistanskoll)

After the project period for <u>Assistanskoll</u> and its financing through the Swedish Inheritance Fund that ended in 2010, the web service has continued to increase in content and reach. <u>Assistanskoll</u> offers information, analysis and advice to assistance users, their families and personal assistants in the choice of assistance provider. Personal assistants are informed about salary levels, collective agreements and terms of employment. LSS administrators can provide assistance to assistance users and their families via <u>Assistanskoll</u>. <u>Assistanskoll</u> keeps the public updated on the changes that are taking place in legislation, the political game around assistance, case law and market development.

At the end of 2020, 207 personal assistance providers participated in *Assistanskoll's* comparison service (203 non-municipal and 4 municipal). In addition to this, 28 personal assistance providers are listed who have not provided information. *Assistanskoll's* website had approximately 816,000 page views during the year (761,000 in 2019 - an increase of 7%) The number of different visitors was 274,000 (against 229,000 in 2019 - an increase of 19.5%). This exposure makes *Assistanskoll's* website and newsletter an interesting forum also for advertisers who now cover *Assistanskoll's* running costs.

<u>Assistanskoll's newsletter</u>, edited by Kenneth Westberg, is published approximately once a month and has achieved a market-leading position in monitoring developments in personal assistance in Sweden. Our articles and other information are often quoted. The newsletter reaches 5,000 email addresses. The target groups are assistance users, their relatives and assistants, assistance organizers, disability organizations and their journals, trade unions, LSS administrators, government officials and politicians at all levels.

There is a growing interest in our information pages and guides. For example, our comparison of collective agreements, the guides Coronavirus, Covid-19 and personal assistance, Working as an assistant, Overtime compensation for personal assistants, What personal assistants get paid, Recruiting personal assistants, Overtime compensation for personal assistants, What personal assistants get paid, Recruiting personal assistants assessment are very popular pages.

Assistanskoll also has a page with comprehensive statistics on the number of people entitled to assistance, new grants / rejections, costs for assistance and how many people entitled to assistance have chosen private companies, municipalities, cooperatives, etc.

Examples of activities on the Assistanskoll website during the year:

- o We have documented what happened during the Corona / Covid 19 pandemic with interviews, statistics and more, and a guide for this was made: <u>Coronavirus</u>, <u>covid-19 and personal assistance</u>.
- o 159 news articles on personal assistance have been published on the website.
- o Two columnists: Nora Eklöv and Thomas Juneborg, write regularly at Assistanskoll.

Other on-going activities and more about the institute

The library, the PA-network, PA-tips and Fashion Freaks

<u>ILI's online full-text library</u> offers authors the publication, exposure, and secure archiving of their work, such as articles in scientific journals, reports, handbooks, and lectures on Independent Living and related topics. At present, the searchable library contains just over 600 documents, of which the majority are in English, about 200 Swedish and about 100 in other languages, mostly German, French and Spanish. We have, for example, a number of bibliographies, which the British researcher M. Miles asked us to publish, about the treatment of people with disabilities in Asian cultures.

<u>The PA-network</u> disseminates information about personal assistance in Sweden through articles and summary texts in English, as well as information about the situation for assistance users in other countries. We often get appreciative comments from readers in different countries. Communication with readers also includes advice based on the content of the articles.

<u>PA-tips.se</u> (personal assistance tips, formerly Assistance tips) is about collecting, documenting (with text and image, video or drawings) and disseminating tips, challenges and examples that assistance recipients and their assistants have developed for various assistance situations. The project had previous project support from the Swedish Inheritance Fund.

<u>Fashion Freaks</u> - your online rehearsal room is about fashion, clothing and vanity from a sedentary perspective. Fashion Freak's basic idea is that people in wheelchairs are as vain as everyone else. We are all unique individuals with the right to their own taste and style. At the same time, it is almost impossible to find stylish clothes sewn for "sitting" shapes. Fashion Freaks is a wardrobe full of custom basic patterns, sewing instructions, descriptions of how to customize ready-made clothes and much more - all to suit wheelchair users. Fashion Freak's website, which is available in both Swedish and English, previously had project support from the Swedish Inheritance Fund and has continued to have many visitors to the site, about 400 people per day, half of whom are from Sweden.

Conferences / seminars / study visits / training initiatives and participation in other actors' events

During the year, a number of conferences, seminars, study visits and training initiatives were arranged, as well as ILI's staff participating in the events of other organizations/actors. Due to the pandemic, the vast majority were switched to digital events, sometimes with some change in the content, but this has not meant fewer events than planned during the year. Below is a selection:

- o 20/1 <u>Lecture on Article 19</u> as a tool for the STIL activists in Jönköping (Thomas Hammarberg was prevented from coming)
- o 27/1 Co-arrangement of A19 seminar with STIL: <u>How do we use the CRPD to demand rights?</u> incl. launch of the essay on the Article 19 Convention on the Right to Work by Susanne Berg and Ola Linder. Part 1, part 2, part 3.
- o 30/1 Meeting with migrant disability group
- o 3-6 /2 UNHCR / IDA conference DRW lectured
- o 6/2 DRDN Webinar "Aging with disabilities in the community"
- o 12/2 DRW Conference in collaboration with Infoteket in Uppsala
- o 19/2 DRW participated in Hjärnkoll's final conference
- o 29/2 DRW lecture SRF Reference group
- o 6-8 /3 DRW Women's group weekend meeting with peer support
- o 10/3 ILI Meeting with Human Rights Watch
- o 12/3 DRW study visit Sumika 6
- o 16/3 ILI / ENIL webinar on Independent Living
- o 23/3 DRW meeting about Corona
- o 26/3 Article 19 contributed speakers at Funktionsrätt Sweden's <u>premiere webinar</u> in the series Respect for rights?
- o 27/4 meeting with Tilloq Greenland on cooperation
- o 5/5 DRW webinar on European Independent Living Day Disabled Refugees and Liberty o 6/5 DRW and NKA webinar Relatives and support
- o 8/5 The final conference of the Vinnova project
- o 26/5 DRD webinar on Legal Clinics a tool to promote disability rights.
- o 10/6 DRW Photovoice exhibition

- o 25/6 Article 19 contributed with speakers to the Funktionsrätts <u>Sweden's webinar on Articles 12</u> and 19 of the CRPD.
- o 2/7 Article 19 co-arrangement with Funktionsrätt Sverige and Disability Rights Defenders Sweden: Discrimination according to the CRPD general comment 6 and how should discrimination be reported? part 1, part 1, part 2.
- o 25/8 Article 19_co-arrangement with Funktionsrätt Sverige on active involvement in accordance with the CRPD.
- o 25/8 Webinar with DPAC- UN Inquiries
- o 14/9 ENIL's member meeting with Nordic countries incl. ILI
- o 1/10 DRW final conference with actors in the Gothenburg area
- o 13/10 Round table discussion with Transcultural Center and DRW
- o 19/10 DRW education Mamma Pappa Lam
- o 23/10 Arrangement of workshop on the accessibility directive and compliance mechanisms. o 27/10 Article 19 / ILI co-arrangement with Funktionsrätt Sweden on Accessibility according to the CRPD general comment 2; part 1, part 2.
- o 5/11 DRD kick-off meeting with Nordic focus
- o 17/11 DRD / ENIL / Art 19 webinar Legal Remedies
- o 19/11 Article 19 training for the County Administrative Board of Skåne's disability network o 25/11 DRW training on family reunification
- o 25/11 DRW and Interact conference
- o 26/11 DRW final conference with actors in the Stockholm area
- o 1/12 DRW training with Forum Skill theme employment
- o 3/12 Article 19 / ILI One year later what has happened since the launch of Respect for Rights? with Funktionsrätt Sverige, SKR and Riksdag politicians and others.
- o 16/12 Webinar on the case of Rickard Sahlin v. Sweden

Publications, interviews, consultation responses and appearances in various media

During the year, ILI's staff published news articles, text, images and video material in various media.

- o On <u>Assistanskoll's website</u>, 159 news articles on personal assistance were published during the year. The newsletter was sent out on 11 occasions during the year, which reached about 5,000 recipients. The website had about 816,000 page views during the year.
- o DRW's website had about 5,000 visits in 2020. 6 newsletters were sent out containing a total of 59 news articles, interviews, films and event information. At the beginning of 2020, <u>DRW's Facebook page</u> had 430 likes and 458 followers.
- o During the year, DRW's major method materials were completed: the information handbook "Roads to mutual integration" and the method handbook "Welcome whoever you are". <u>Link to DRW's digital material</u>. The information manual is available as an easy-to-read and audio book. Several of the materials are available in translations into different languages.
- o <u>Article 19 as a tool website</u> had 2020 25,000 visits by 20,000 people; 58 posts were published during the year. Facebook page Article 19 / The law as a tool had 440 likes and 478 followers. At the beginning of 2021, the newsletter had 288 subscribers and went out with 9 issues by 2020.
- o DRD sent out 3 newsletters during the year with short descriptions of legal cases, court decisions, references to legislation, publications, reports and announcements about events, learning and funding opportunities to more than 400 subscribers. The project's Facebook group grew in 2020 to 2,300 members from over 100 countries.
- o 27/1 Reply to the linguist Lars Melin
- o 17/3 Research interview Moona Ketola Refugee women with intellectual impairment. o 7/4 Interview Dutch researcher Wouter Durson on PA services
- o 14/5 Interview by IDA about Corona
- o May: TRIPS interviews and social media analysis

- o May: A guide to arranging webinars was published
- o June: Survey Report on Remedies was published by DRD and Article 19 as a tool
- o September: Interview with the Red Cross and the DRW team on migration
- o 18/9 Interview with EDF Mapping Disability inclusiveness of EU states International Development Cooperation and Humanitarian Aid
- o 24/9 Interview with EASPD, DI and Europe
- o November: Contribution to the ongoing government inquiry into the implementation of the Accessibility Directive in Sweden with a focus on compliance with regulations

Policy initiatives 2020:

- 7/12 Consultation on A long-term sustainable migration policy (SOU 2020: 54)
- 11/11 Response to the Review of support provisions according to LSS and assistance compensation (SOU 2018: 88)
- 19/10 Debate article on hate crimes due to disability
- 28/9 Press release: Rickard Sahlin with the support of DRDS and others. wins against Sweden in the UN
- 23/6 Consultation response to the Review of the profession of personal assistant (SOU 2020: 1)
- 18/6 Joint Swedish civil society response and separate additional response to special procedures joint Covid-19 questionnaire
- 17/6 Referral response on the memorandum "Temporary provisions on certain carrier allowance due to the disease covid-19"
- 24/4 Press release: Decisions in LSS and SoL must continue stop SKR's proposal
- 23/3 Cooperation within the Human Rights network for an independent national MR institution, including coordination of <u>an open letter to the Prime Minister</u>

Collaboration with the association Disability Rights Defenders Sweden (formerly MLSV)

The association With the law as a tool (MLSV) was formed in 2015 on the initiative of ILI and others and is run under its own auspices as a member-based non-profit association. The association's name was changed to Disability Rights Defenders Sweden (DRDS) at the annual meeting 2020 after inspiration from ILI's project Disability Rights Defenders. The association conducts discrimination cases related to disability, if necessary in court. In addition to this, the association informs about civil and human rights for people with disabilities, provides advice and information about disability discrimination.

In 2020, ILI collaborated with DRDS through seminars, communication and the project Independent Living via Interpreting Services in working life and beyond, which is funded by Independent Living Development (ILU) and extends to March 2021. As a result of the association being the driving force in the case of Rickard Sahlin vs. Sweden, and the decision from the UN Committee on the Rights of Persons with Disabilities means that Sweden has received criticism, much of the collaboration has revolved around this.

Examples of ongoing legal cases:

- o Failure in stop announcements on buses in several cities, continuation of work after previous settlement.
- o Discrimination against students with dyslexia in the national tests.
- o Lack of access to payment machines at unmanned petrol stations.
- o See more at https://lagensomverktyg.se/rattsarenden/.

Collaboration with the disability movement in Sweden and internationally

Through the ILI long joint work with other organizations to expand and defend our civil rights and increase our concrete opportunities to live like others, ILI has built up good contacts within Swedish civil society in the disability area. With this broad network, we have easily been able to find co-applicants for project applications and for other collaboration. Increasing collaboration takes place between organizations prior to consultation opinions and other political initiatives, such as in the work for an independent HR institution. We also have good international contacts through our long-term commitment to the international Independent Living movement within Disabled People's International and ENIL, the European Network for Independent Living, as well as through many collaborative projects and mutual exchanges of experience.

Over the years, ILI has become an international information and contact agency, which has helped us expand our network and deepen our cooperation with other organizations. In this way, together with many other actors, we have been able to contribute to an increased pace of development in the field of disability in a number of countries in terms of policy for accessibility, personal assistance, technical aids and work. The questions can concern projects, literature sources, mediation with other organizations and experts or concern individuals who need support and advice.

ILI's Chairman of the Board, Adolf Ratzka, has during the year been:

- Member of the Overseas Editor and peer reviewer of the journal Disability and Society, UK. Member of the International Advisory Council, Ecoplan.
- o Board member of the Foundation in memory of Rolf Bergfors.

ILI's Director, Jamie Bolling, has during the year been:

- ENIL's co-chairman, member of ENIL Management Team and Audit Committee. Board member of Bente Skansgård's Independent Living Fund.
- o Vice Chairman of MyRight's Board.

ILI's staff

In 2020, there was a rich variety of skills and experience in the ILI workforce, several persons with disabilities, an even distribution between the sexes, a large spread in age and with people coming from different countries. In 2020, ILI's staff consisted of the following people, most of whom worked part-time, some only for short periods:

Adolf Ratzka, ILI's founder together with Rolf Bergfors, chairman of the board and project employee in Disability Rights Defenders. On leave during the year.

Algren Morgan, project employee at Assistanskoll and Disabled Refugees Welcome.

Erik Tillander, journalist and project employee in Assistanskoll and Article 19 as a tool.

Gabriel Boulos, lawyer and project employee at Disabled Refugees Welcome until the end of August.

Jamie Bolling, director and project manager for Disabled Refugees Welcome, TRIPS, DI project and project staff in Article 19 as a tool.

Julius Mvenyi Ntobuah, project staff member at Disabled Refugees Welcome until the end of August.

Kenneth Westberg, journalist and project manager for Assistanskoll.

Linda Robertsson, Office manager incl. administration, personnel and finances.

Mari Siilsalu, project staff member at Article 19 as a tool.

Ola Linder, lawyer and project manager for Article 19 as a tool.

Philip Day, webmaster, database programmer and project staff member at Assistanskoll, the Complaints Service and Article 19 as a tool.

Rahel Abebaw Atnafu, project staff member at Disabled Refugees Welcome.

Riitta-Leena Karlsson, project staff member at Disabled Refugees Welcome until the end of August.

Selina Grießer, project manager for Disability Rights Defenders and project staff member at TRIPS and support person within Disabled Refugees Welcome.

Sooz Romero Orellana, communicator and method developer for Disabled Refugees Welcome until the end of August.

During the year, the following people were interns at ILI:

Annemarie Isbert, ERASMUS Fellow with contributions mainly in Disability Rights Defenders. **Dilek Hakbilen**, with contributions in Disabled Refugees Welcome.

In addition, work initiatives have been carried out on a consulting basis and through short-term / temporary freelance assignments. Consultancy assignments that ran for longer periods were performed by:

Anna Bruce, Raoul Wallenberg Institute, in the project Article 19 as a tool.

Doro Riedel, with DRW's photovoice venture.

Elena Quiñonez and Sebastian Ferrer, accounting services.

Susanne Berg, text writing and translation assignment.

Suzanne Elmqvist, in the project Article 19 as a tool.

Funding

Thank you from ILI to:

- <u>Allmänna Arvsfonden</u> (Swedish Inheritance Fund) that funded the projects Article 19 as a tool and Disabled Refugees Welcome.
- <u>Bente Skansgårds Independent Living Fund</u> that contributed project funding to Disability Rights Defenders.
- <u>Bidragsstiftelsen</u> that funded the DI project
- The European Commission that funded the TRIPS project.
- <u>STIL/</u>ILU, Stiftarna av Independent Living i Sverige that contributed funding to ILI's activities as well as the project Independent Living via interpreting services in working life and beyond.
- <u>Vinnova</u> that funded the project Compete with usability and accessibility, where ILI was one of the project partners.

In addition, ILI's activities were funded by banner advertisements on Assistanskoll.se and private donations.

Board composition and meetings

Adolf Ratzka, Stockholm, introduced the Independent Living philosophy to Scandinavia 1983; founder of <u>STIL</u> and its chairperson until 1995; ENIL's first chairperson 1989-1992; founder of <u>Independent Living Institute</u>, together with <u>Rolf Bergfors</u>, <u>GIL</u>, and the director of ILI from the start 1993 until September 2017. Adolf is the boards' chairperson.

Bengt Elmén, Stockholm, author, debater and lecturer; board member of STIL; was office manager for STIL 1987-1991.

Gilla Andersson, Lidingö, substitute for Bengt Elmén; board member of STIL since 2006 and its vice-chairperson since 2016; chairperson of Swedish Rheumatism Association, Lidingö chapter since 2016.

Jamie Bolling, Härnösand, human rights defender focusing on disability issues; director of ENIL 2009-2017; former member of Green party's national board; board member of Bente Skansgård Independent Living Fund and MyRight.

<u>Judith E. Heumann</u>, Washington DC, USA, one of the premier internationally recognised Independent Living activists known, among other things: for her role in the movement's 28 days occupation of the Federal Building in San Francisco that forced the Federal Government to sign Section 504 of the Rehabilitation Act of 1973; for her work at the <u>Center for Independent Living Berkeley</u> (where she laid the foundation of today's Disability Rights Education and Defense Fund); as promoter and Director, together with <u>Ed Roberts</u>, for the <u>World Institute on Disability</u>; as Assistant Secretary for the Office of Special Education and Rehabilitation Services, <u>US Department of Education</u> 1993–2001; as <u>World Bank Group's</u> first Advisor on Disability and Development 2002-2006; as Director, Department of Disability Services, District of Columbia; ad Special Advisor on Disability Rights for the US State Department 2010–2017.

Kapka Panayotova, Sofia, Bulgaria, chairperson of <u>ENIL</u>, the European Network on Independent Living; founder and director of the <u>Center for Independent Living</u>, <u>Sofia</u>.

Miro Griffiths, Leeds, UK, teaching fellow at Leeds University on disability services; former researcher at Liverpool John Moores University, 2015-2018; awarded an MBE (Member of the Order of the British Empire) 2014 in recognition of his services to disabled people; member of the British Sociological Association and involved in the Work Group on Disability; member of the Equality and Human Rights Commission Disability Advisory Committee; member of the Liverpool City Region Fairness and Social Justice Advisory Board; member of the International Independent Living research Network. Miro was appointed to the board in November 2019.

During 2020, the board held two board meetings, the 10th of May and the 8th of November, both in the form of digital conference calls. In addition, contact has been made through email, telephone and individual meetings.

Adolf Ratzka Bengt Elmén Jamie Bolling Judith Heumann Kapka Panayotova Miro Griffiths

Stockholm, 2021 -