

Annual Report 2021

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 2021, 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 more 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

Anmälningstjänsten (The Disability Discrimination Reporting Service)

Anmälningstjänsten helps individuals and organizations to report discrimination cases to the Discrimination 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 5,000 visits from about 4,000 people who made 34 claims (more than in 2020). The service was administered through funding from the Swedish Inheritance Fund via the project Article 19 as a tool. During 2021 an app was constructed which can be installed on a smartphone.

Article 19 as a tool (Artikel 19 som verktyg)

The project Article 19 as a tool started in 2019 and continues until March 2022 with funding by the Swedish Inheritance Fund. 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 2021, the work was based on the three previously established main tracks: 1) raising awareness of rights to 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. Ola Linder left ILI in September 2020 as well as the lead for the project. He was replaced by Jamie Bolling as the project manager.

Various activities have been carried out with partner municipalities and civil society organizations. This includes training, discussion groups on Article 19 and the situation for rights holders, study circles as well as policy development and consultation responses to bills. ILI and Article 19 have also contributed to the Swedish parallel reporting of the Economic, Social and Cultural rights to the UN. Information has been developed continuously through articles and posts on the website - lagensomverktyg.se and in social media. The legal gap analysis has continued to develop. The Study Material was updated through the discussion groups and can be found on the web. The follow-up

tool has continued its development phase as well as the [Self-determination barometer](#). Discussion groups have continued to contribute to the work with the follow-up tool and the Self-determination barometer. On the 17th of November a concluding conference was held with the municipality of Partille on the cooperation with Article 19 as a tool. The counseling has continued to attract persons regularly, with 56 cases being registered in 2021, several of these have been active through recurring contacts.

The collaboration with RWI has had a very positive synergy effect with the cooperation through a Law Clinic that took place. During the fall, students from the law clinic have contributed with practical work for a person receiving counseling through Article 19 as a tool. This is part of 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. These student reports contribute to the legal process for individuals and at the same time are important for rights processes in the Article 19 as a tool project.

Article 19 as a tool has cooperated with DRW/DHR and DRW/UNHCR (see below) holding several workshops for refugees with disability needing support and who speak Arabic, Amharic and Dari. The work in the workshops show that people do not understand the difference between support given through the municipalities and the national insurance board - Försäkringskassan. They do not know how to fill in applications for support and need help. These workshops have been based on the CRPD, and particularly article 19 and its implementation in Sweden.

[The website for the project](#) had 27,000 visits from 22,000 people during 2021 which was an increase from 2020. The website is the same as for the previous project - The law as a tool. The [Facebook page Article 19 / The law as a tool](#) had 532 followers, the newsletter had 290 subscribers and went out with 9 issues during the year. Three episodes of the podcast "Whose choice?" have been published in 2021.

Assistanskoll

After the project period for [Assistanskoll](#) and its financing through the Swedish Inheritance Fund ended in 2010, the web service has continued to increase in content and scope. Assistanskoll 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 salary agreements and terms of employment. LSS administrators can provide guidance to assistance users and their families via Assistanskoll. Assistanskoll keeps the public updated on the changes that are taking place in legislation, the political game around assistance, case law and market developments.

At the end of 2021, 196 personal assistance providers participated in [Assistanskoll's](#) comparison service. (193 non-municipal and 3 municipal). In addition, 19 providers are listed who have not provided information. [Assistanskoll's](#) website had about 675,000 page views during the year (816,000 in 2020 - the pandemic caused more traffic in 2020). The number of unique visitors was 213,000 (against 274,000 in 2020). This exposure makes [Assistanskoll's](#) website and newsletter an interesting forum for advertisers who now cover Assistanskoll's running costs.

[Assistanskoll's newsletter](#), 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 4,600 e-mail addresses. The target groups are assistance users, their relatives and assistants, assistance

providers, disability organizations and their publications, trade unions, LSS administrators, government officials and politicians at all levels.

Assistanskoll has a large number of 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 do personal assistants have in salary?](#) [Recruiting personal assistants](#), [Organize your own assistance](#) and [Prepare for your assistance assessment](#) are very popular pages.

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

Examples of what happened on the Assistanskoll website during the year:

- We have documented what happened during the Corona / Covid 19 pandemic with interviews, statistics and more in the guide: [Coronavirus, covid-19 and personal assistance](#).
- We have reported on, for example, the submissions to the government report “Strengthening the right to assistance” and the inquiry into whether local government or the national social insurance agency should be responsible for personal assistance.
- 122 news articles on personal assistance have been published on the website.
- Two columnists: Nora Eklöv and Thomas Juneborg, write regularly at Assistanskoll.

The DI-project - a paper on de-institutionalization

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

The publication intends to describe Sweden's history of and the process of closing institutions. The publication also intends to describe the importance of support measures according to LSS and the Independent Living movement's work and development of personal assistance. This work was important for the Swedish reform at the closure of large institutions as the support was regulated with the LSS reform and with personal assistance. The paper also intends to highlight today's challenges with risks for institution-like working methods and reinstitutionalization. The publication is to be completed during the spring of 2022.

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 project is financed by the Bente's Skargårds Independent Living Fund. 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, functional 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'.

During 2021, the Facebook group grew to 2,302 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.

Webinars have proven to be a successful way to spread information on DRD but also on rights and rights processes. DRD was active in the ENIL Freedom Surf which took place in September 2021. Planning has taken place for a digital meeting with the Nordic Independent Living Movement and what is happening in the field of personal assistance and the implementation of the CRPD. This conference will be in February 2022.

Disabled Refugees Welcome (DRW)

[Disabled Refugees Welcome](#) was an integration project carried out between 2017 - 2020 financed by the Swedish Inheritance fund. Since the activity is included on a smaller scale within the general work of ILI as well as through project cooperation building on the experience of DRW (see below on the cooperation with UNHCR and DHR). During the year the Swedish Inheritance fund approved the project "Reciprocal integration and the right to work" which will build on the DRW project's experience with the focus on employment. This project will start in April 2022 with a part of the preparatory work taking place in 2021.

The purpose of DRW was 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.

DRW's methodological material: the information handbook "Roads to mutual integration" and the method handbook "Welcome whoever you are", collected DRW's conclusions, the target group's needs, analysis of the situation and measures needed to achieve mutual integration. These have been spread during the year to be used by actors working with refugees/migrants with disability.

Contact with the target group continues. People take contact with ILIs support and counseling service through the project Article 19 as a tool. DRW was presented at several conferences during 2021. The website and social media have also continued to spread information on the results of DRW. The website had 3,000 visits and the Facebook page 497 followers.

DRW/DHR on the integration of migrants with disability

The project Integration of migrants with disability is a cooperation with DHR with financing from [the Grant Foundation \(Bidragsstiftelsen\)](#). The work started in 2001 and will continue until March 2023. The aim of the project is to promote the integration of disabled migrants through knowledge and experience regarding the double competence: knowledge of disability issues and migration issues, and through the inclusion of the target group in the Swedish Civil Society.

DRW/UNHCR - seminar series

ILI/DRW were contacted for a cooperation with the UNHCR Representation for the Nordic and Baltic Countries. The project carried out a series of workshops to reach refugees with disabilities. Five workshops were carried out at the end of the year in cooperation with Article 19 as a tool. See Article 19 as a tool (above) for more information on this short project.

Independent Living via interpreting services in working life and beyond

With funding from the Independent Living Development Foundation (ILU), ILI together with the association Disability Rights Defenders Sweden ran a project on the deaf's right to cash support for sign-language interpretation, which was based on conclusions and recommendations of the UN

Committee on the rights of persons with disabilities in their decision in the Rickard Sahlin case against Sweden. 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 were analyzed.

The project closed with a seminar in March of 2021 and a promemoria with the analysis and the discussions on solutions from the principles of Independent Living.

TRIPS

The Independent Living Institute (ILI) is participating in an EU-financed 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. During the year the Stockholm group took contact with various actors to spread information on the project. Through the University in Lund a project financed by Vinnova developed that could take forward the results of the work in Sweden with TRIPS (see below).

TRIPS/Digital travel support for public transport for travelers with a variation of needs

Digital travel support within the public transport for travels with a variation of needs is a project financed by [Vinnova](#) carried out in cooperation with the Universities of Lund and Malmö. The project's goal is to increase accessibility of the public transport to create a change in behavior so more persons will choose to travel with the public transport giving a more sustainable mobility and more healthy travel habits. The project started on the first of November 2021 and will end on the first of May 2022. A part of the project is to find partners for cooperation for a longer project with the same goal.

Other on-going activities and more about the institute

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

[ILI's online full-text library](#) 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.

[Fashion Freaks](#) - 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.

[The law as a tool](#) ended in 2019 and had been funded through the Swedish Inheritance Fund. Operations have continued to some extent since. 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. The project continues to live through the website but also through the developments within Article 19 as a tool. Several organizations still refer persons to the ILI counseling and for the search of juridical support to carry out cases which was the work carried out in the Law as a tool.

[The PA network](#) 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. In spite of the fact that most of the materials are getting older there are still appreciative comments from readers. Communication with readers also includes advice based on the content of the articles.

[PA-tips.se](#) (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.

Organization of conferences/seminars/study visits/training activities and participation in events organized by others

During the year, a number of conferences, seminars, study visits and training activities were organized and ILI staff participated in events organized by other organizations. Due to the pandemic, the vast majority of these were conducted as digital events. A selection is listed below:

- 14/1 and 22/1 Workshops with the TRIPS project on [Future mobility of persons with disabilities](#)
- 17/2 [Interview](#) on DRW and women by EDF - European Disability Forum
- 18/2 Webinar in cooperation with The Swedish Disability Rights Federation on [Alternative Reporting](#)
- 22/2 OHCHR International Conference on De-institutionalization with special rapporteur on the rights of persons with disability
- 24/2 UNHCR International Conference on Migrants with Disabilities
- 19/3 Training with Lika Unika Akademi for Arabic-speaking migrants with disabilities
- 23/3 Consultation group with RFSL Stockholm on the development of Article 19 as a tool for assessment
- 23/3 Final seminar at ILI/DRDS [Communication support and independent living/](#)
- 30/3 Upplands Väsby discussion group on the development of Article 19 as a tool for assessment
- 22/4 Partille discussion group on the development of Article 19 as a tool assessment tool
- 19 - 21/4 Article 19 project at the Human Rights days with a seminar in cooperation with STIL: [Do you have power over your life? A question of where you live.](#)

- 21/4 DRW at the Human Rights days together with Lika Unika Akademi on the Right to Housing
- 27/4 ENIL meeting on EU Disability Strategy
- 28/4 Reference group meeting for the Article 19 as a tool project
- 30/4 Article 19 as tool meeting with Swedish Association for the Swedish municipalities and regions
- 4/5 International Center for Local Democracy - Jamie Bolling lectures on IL
- 5/5 International IL Day - collaboration with ENIL, ULOBA on the history of Independent Living, panel discussion
- 12/5 ENIL North on ENIL strategy
- 25/5 Ola Linder at EU Regional Consultation
- 4-5 /6 ULOBA Pride Parade - digital participation with Jamie Bolling and Adolf Ratzka
- 14/6 Council of State Parties - Jamie Bolling and Adolf Ratzka participate
- 18/6 TRIPS workshop
- 30/8 Seminar in RWI Law Clinic to introduce ILI cases to students
- 8/9 Lika Unika Akademin Seminar with Ola Linder leading discussions
- 10/9 and 20/9 Conference on personal assistance for Poland's new legislation
- 22/9 Photovoice exhibition at [ENIL Freedom Surf](#)
- 23/9 Tutoring for RWI Law Clinic students to plan work on ILI cases
- 23/9 ENIL Freedom Surf - presentation of the projects Art. 19 as a tool, DRD and DRW
- 28/9 Seminar for consultation with the Ministry of Social Affairs regarding Sweden's reporting on economic, social and cultural rights.
- 4/10 ILI meeting with the Swedish Church on cooperation on migrants with disabilities
- 7/10 Tutoring for RWI Law Clinic students to plan work on ILI cases
- 7/10 Riitta Leena Karlsson on De-institutionalization at Bosse Council, Support and Knowledge Center's 40th anniversary celebration
- 21/20 Reference Group Meeting with The Swedish Disability Rights Federation on Counselling
- 25/10 [Opening of the Photovoice exhibition](#) at the ILI office
- 29/10 Tutorial for RWI Law Clinic students on working with ILI cases
- 3/11 Upplands Väsby discussion group on Article 19 as a tool for assessment
- 9/11 Testing of the assessment tool with Partille municipality
- 10/11 KUI Conference on LSS with Ola Linder
- 15/11 Workshop DRW/UNHCR/Art. 19 Disability and Culture
- 17/11 Art. 19 Final conference with Partille municipality
- 19/11 Workshop DRW/UNHCR/Art. 19 Disability and Civil Society
- 27-28 /11 DRW/UNHCR/Art. 19 weekend conference Arabic-speaking group
- 2/12 MFD and County Council Participation Days with Jamie Bolling on DRW
- 6-7/12 The Human Rights Days in Gothenburg with Photovoice exhibition and Art. 19 as a tool seminar [Democracy + security system = true/](#)
- 10/12 ULOBA training on ILI and ENIL

Publications, interviews, consultations and media appearances

During the year, ILI staff published news articles, text, images and moving images in various media.

On the [Assistanskoll](#) website, 122 news articles on personal assistance have been published during the year. The newsletter was sent out on 11 occasions during the year, reaching approximately 4,600 recipients. The website had approximately 675,000 page views during the year.

[DRW's](#) website had about 3,000 visits in 2021. DRW's [Facebook page](#) has 464 likes and 497 followers. DRW has contributed a chapter to a book published by UNHCR in the spring of 2021, a [handbook](#) on the inclusion of asylum seekers with disabilities in which the DRW project is highlighted as a good example.

Article 19 as a tool [website](#) had 2021 - 27,000 visits from 22,000 people; 58 posts/news articles were published during the year. The Facebook page Article 19/Law as a tool had 519 likes and 563 followers, the newsletter had 290 subscribers and sent out 9 issues in 2021.

The project launched the first version of the [assessment tool](#) on the Article 19 as a tool webpage. After conducting some study circles based on the Article 19 as a Tool study material, the study material was revised and [the new version](#) was published on the project website.

DRD sent out [a newsletter](#) during the year focusing on Kapka Panayotova and the work she and others are doing within ENIL and around the world. The newsletter went out to 580 subscribers. The project's Facebook group grew in 2021 to 2,300 members from over 100 countries.

Policy initiatives 2021:

- 29/11 [Consultation response on the National Board of Health and Welfare's proposal to amend the general guidelines \(SOSFS 2014:2\)](#)
- 1/11 [Consultation opinion on the report \(SOU 2021:44\) Accessibility Directive](#)
- 8/10 [Consultation statement on the report SOU 2021:36 Gode män och förvaltare - en översyn](#)
- 1/10 [Consultation response on the report \(SOU 2021:37\) Strengthened right to personal assistance](#)
- 3/5 [Consultation opinion on the interim report More effective enforcement of the Discrimination Act - active measures and the area regulated by the Education Act \(SOU 2020:79\)](#)
- 12/4 [Consultation opinion on A matter of common concern \(SOU 2020:46\)](#)
- 31/3 [Consultation opinion on the memorandum "Payment of compensation for personal assistance only if authorised"](#)

Collaboration with the National Knowledge Centre for Deafblindness (NKCDB)

Since January 2021, ILI has been part of an expert council organized by the NKCDB, where ILI's lawyer has contributed legal expertise in the role of supporting the regions' counselors in particular on legal issues related to current legislation in the field. The assignment also involves developing understanding of legal rights issues in general in relation to people with disabilities.

Collaboration with Disability Rights Defenders Sweden (DRDS)

The association Med lagen som verktyg (MLSV, The law as a tool) was founded in 2015 on the initiative of ILI and others and operates under its own auspices as a membership-based non-profit association. The name of the association was changed to [Disability Rights Defenders Sweden \(DRDS\)](#) at the annual meeting in 2020, inspired by ILI's Disability Rights Defenders project. The association pursues

discrimination cases related to disability, if necessary in court. In addition, the association informs about the human rights of persons with disabilities, provides advice and information about disability discrimination.

ILI has in 2021 interacted with DRDS through seminars, exchanges of experience and in the project Independent Living via interpreting services in working life and beyond, funded by Independent Living Development Foundation, ILU, which ran until March 2021. As a result of the association being a driving force in the case Rickard Sahlin v Sweden and the final decision of the UN Committee on the Rights of Persons with Disabilities criticizing Sweden, much of the interaction has revolved around this.

Examples of ongoing legal cases:

- The right to support and adaptations in preschool and primary school.
- Discrimination against pupils with dyslexia in national examinations.
- Lack of availability of payment machines at unmanned service stations.

See more at <https://lagensomverktyg.se/rattsarenden>.

Collaboration with the disability movement in Sweden and internationally

Through our 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 our field. With this broad network, we have been able to easily find co-applicants for project applications and other cooperation. There is increasing cooperation between organizations in preparation for consultation statements and other political initiatives. We also have good international contacts through our long-standing involvement in 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 broker, which has helped us to 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 accessibility policies, personal assistance, assistive technology and employment. Issues may relate to projects, sources of literature, liaison with other organizations and experts, or individuals in need of support and advice.

Reference groups in which ILI has participated:

- [Funktionsrättsbyrå - Functional rights](#).
- [Nothing about us without us](#) - The Swedish Foundation for Human Rights/ Handikapp-historiska föreningen.
- [Lika Unika Akademi](#) - United Nations Association in Sweden.

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

- Member of the editorial board ("Overseas Editor") and peer reviewer for the journal ("Overseas Editor") "[Disability and Society](#)", UK.
- Member of the International Advisory Council, Ecoplan.
- Board member of the [Foundation in memory of Rolf Bergfors](#).

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

- [ENIL](#) Co-Chair, member of the ENIL Management Team and Audit Committee.
- Board member of [Bente Skansgård's Independent Living Fund](#).
- Vice Chairman of the [Board of MyRight](#).

ILI's staff

In 2021, 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 2021, ILI's staff consisted of the following people, most of whom worked part-time and some only for short periods:

Algren Morgan, project member of Assistanskoll and Disabled Refugees Welcome.

Erik Tillander, journalist and project member of Assistanskoll and Article 19 as a tool.

Jamie Bolling, director and project manager for Disabled Refugees Welcome, TRIPS, DI-project and from September project leader for Article 19 as a tool.

Kenneth Westberg, journalist and project manager for Assistanskoll.

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

Mari Siilsalu, project member of Article 19 as a tool.

Ola Linder, lawyer and project manager for Article 19 as a tool until the end of September.

Philip Day, webmaster, database programmer and project member of Assistanskoll, the Disability discrimination reporting service and Article 19 as a tool.

Rahel Abebaw Atnafu, project member of Article 19 as a tool, the DRW/DHR project and DRW/UNHCR project.

Selina Grießer, project manager for Disability Rights Defenders. On parental leave in 2021.

Stefan Käll, lawyer and project member of Article 19 as a tool from September.

In addition, work has 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, with contribution to Article 19 as a tool.

Elena Quiñonez and Sebastian Ferrer, accounting services.

Suzanne Elmqvist, with contribution to Article 19 as a tool.

Riitta-Leena Karlsson, with contribution to the DI-project.

During the year the following persons have carried out their research while located at ILI:

Daniela Komanická, Charles University in Prague - research on personal assistance.

Mabel Giraldo, Catholic University of the Sacred Heart in Milan - research on self-determination.

Funding

Thank you from ILI to:

- [Allmänna Arvsfonden](#) (Swedish Inheritance Fund) that funded the projects Article 19 as a tool and Disabled Refugees Welcome.
- [Bente Skansgård's Independent Living Fund](#) that contributed project funding to Disability Rights Defenders.
- [Bidragsstiftelsen](#) (the Grant Foundation) that funded the DI-project.

- The European Commission that funded the TRIPS project.
- [STIL/ILU](#) that contributed funding to ILI's activities as well as the project Independent Living via interpreting services in working life and beyond.
- [UNHCR Representation for the Nordic and Baltic Countries](#) that financed the DRW/UNHCR - seminar series.
- [Vinnova](#) that funded the project Digital support for public transport for travelers with a variation of needs.

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 in 1983; founder of [STIL](#) and its chairperson until 1995; ENIL's first chairperson 1989-1992. Adolf together with Rolf Bergfors founded [GIL](#) and the [Independent Living Institute](#) and was the director of ILI from the start 1993 until September 2017. Adolf is the chairperson of the board.

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 with focus on disability issues; director of ENIL 2009-2017; former member of Green party's national board; board member of STIL and MyRight.

Judith E. Heumann, 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 [Center for Independent Living Berkeley](#) (where she laid the foundation of today's Disability Rights Education and Defense Fund); as promoter and Director, together with [Ed Roberts](#), for the [World Institute on Disability](#); as Assistant Secretary for the Office of Special Education and Rehabilitation Services, [US Department of Education](#) 1993–2001; as [World Bank Group](#)'s 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, founder and director of the [Center for Independent Living, Sofia](#). Kapka died suddenly on October 14 2021. An article was written in the DRD newsletter ([Den sorgliga nyheten om en av våra mest betydelsefulla medkämpar Kapka Panayotova.](#))

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.

During 2021, the board had one per capsulam decision by email on the 22 of April and one meeting via zoom on May 16. A board meeting was planned for December but was moved to January. In addition, contact has been made through email, telephone and individual meetings.

Stockholm, 2022 -

Adolf Ratzka

Bengt Elmèn

Jamie Bolling

Judith Heumann

Miro Griffith