

ANNUAL REPORT 2019

Independent Living Institute (ILI) works to promote opportunities for individuals with non-normative abilities for more personal and political power, self-determination, full participation and equality through information, education, lobby and project activities. During 2019, 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.

Project activities

Disabled Refugees Welcome, DRW

[Disabled Refugees Welcome](#) is an integration project carried out by the Independent Living Institute. It is a three-year project financed by Allmänna Arvsfonden. DRW was granted an extension and ends the 31st December 2020. The purpose of DRW is to develop new methods that improve the conditions of reception and integration of newcomers and migrants with various disabilities. During the project, DRW documents the needs of the target group and develops activities that, in the future, can become a natural part of the Swedish migration system.

DRW has been very active during 2019. The project has been presented for many cities in Sweden. An information handbook has been produced. The outline of the method handbook was also begun. Both books were published in 2020. The project webpage and social media channels have continued to disseminate information on DRW's results actively. There is a continuous stream of new individuals looking for DRW's competence. More than 80 case studies on newcomers from their target group have been completed. Several interviews on the project have been published in the media.

Artikel 19 som verktyg (Article 19 as a tool)

2018, Arvsfonden decided to grant funding to ILI's project [Artikel 19 som verktyg \(Article 19 as a tool\)](#) for three years. The project officially started on 1st April 2019. During 2019, suitable personnel and consultants have been recruited and shaped into a cooperating team with various competencies that together contribute well to the implementation of the project plan. The project was jump-started in April by gathering all the cooperating organisations in Stockholm to educate on article 19, get to know each other's activities and needs better and begin to plan the cooperation more concretely. A meeting with the reference group was held in November 2019, and steering group consisting of ILI and Raoul Wallenberg Institute of Human Rights and Humanitarian Law (RWI) has had an ongoing dialogue.

During the year, the work has followed three main tracks: 1) raising awareness of rights among rights-bearers, 2) to find methods to be able to follow-up how Sweden comply with its international commitments, and 3) producing a law proposal for better implementation of the commitments.

Different activities have been carried out together with cooperating municipalities and civil society organisations. It involves both educations, dialogue groups on article 19 and the situation of the rights-bearers, as well as, policy development and consultation responses on government bills. Information has continuously been disseminated through articles and posts on the webpage lagensomverktyg.se and social media. The legal gap analysis is begun, and a guide on individual complaints to the Committee on the Rights of Persons with Disabilities has practically been completed. The monitoring tool is under development, and in consultation, with RWI we have found a good basis with a system for human rights indicators from the Office of the United Nations High Commissioner for Human Rights (OHCHR). The advisory service has grown and attracted many applicants for support; more than 20 incoming cases have been registered at the project during 2019.

The cooperation with RWI has generated a very positive synergy effect through the establishment of a Law Clinic in collaboration between the organisations. ILI and Article 19 as a tool contributed assignments for the students to work at, which have a connection to ILI's strategic work on the implementation of the human rights and improved living conditions for individuals with non-normative abilities. ILI has an ongoing dialogue with RWI and the students to realise the clinic.

[The project webpage](#) had 27 000 visits by 21 000 visitors during the year. It is the same webpage as the project Law as a tool. The Facebook-page Article 19/Law as a tool had 381 followers; the newsletter had 287 subscribers and ten issues during the year (however, two of which belonged to Law as a tool).

Anmälningstjänsten (The Disability Discrimination Reporting Service)

[Anmälningstjänsten \(The Disability Discrimination Reporting Service\)](#) helps individuals and organisations to report cases of discrimination to the [Equality Ombudsman](#) and, when appropriate, the respective municipal building committee. The Disability Discrimination Reporting Service has existed and been developed since the end of the 1990s. During 2019, 18 reported cases were made public and five not public through the Disability Discrimination Reporting Service. The webpage had approximately 10 000 visits from some 9 000 visitors (about two times as many as 2018). Some reported cases were of such integrity-sensitive nature that we have chosen not to publicise them. The Independent Living Institute has made complaints to the Parliamentary Ombudsmen (JO) that several municipalities' handling time is far too long for cases of easily eliminated obstacles, the longest 13 years. During 2019, the exchange of letters continued, and JO issued criticism regarding flawed handling to five municipalities. Of interest is the statement from JO that the cases must be handled efficiently since individuals can have a right to appeal decisions that directly concern them, i.e. be recognised as rights-bearers. The reporting service was 2019 funded by Arvsfonden through the project Law as a tool and Article 19 as a tool.

Lagen som verktyg, MLSV (Law as a tool)

The project financed by Arvsfonden ended the 28th of February 2019. [Lagen som verktyg \(Law as a tool\)](#), MLSV worked to increase the disability movement's access to legal expertise in the areas of education, defence and advancement of work against discrimination of people with disabilities.

The purpose was to contribute to better implementation of the rights of people with disabilities by using the law and case-law as tools against disadvantageous treatment and structural discrimination. Law as a tool, MLSV also collaborated with the non-profit organisation [Med Lagen som verktyg \(Law as a tool Association\)](#) (see below under Other ongoing activities). The collaboration consisted of arranging seminars, disseminating information to members and assisting with administrative and legal tasks.

The dialogue with prominent persons within the anti-discrimination sphere continues during 2019 and 2020 and ILI's work continues to make an impression even after the completion of the project. Some examples are the reviews of municipalities handling of complaints regarding easily eliminated obstacles, as well as, the Equality Ombudsman's lacking supervision regarding employers' work with active measures against discrimination. ILI is continuing its work for the right to access to justice within the project Article 19 as a tool, and contacts with other parts of the civil society and the academic sphere are developed there.

Disability Rights Defenders, DRD

[Disability Rights Defenders](#), DRD is a network of individuals and organisations interested in rights and jurisprudence concerning people with disabilities. The general purpose of the network is access to rights on equal conditions as others. The network disseminates and deepens expert legal knowledge of the rights to people with disabilities, disability organisations, legal professionals and academic legal programmes. The mutual sharing of legal knowledge strengthens the ability to use the law as a tool. We achieve this by bringing people together through our [Facebook-group, Disability Rights Defenders](#). During 2019 the group grew to 780 members from approximately 100 countries. Members share their experiences, methods and advice on how you use the law as a tool. The content of the Facebook-group is summarised in a [newsletter](#) issued a couple of times per year.

DRD held two successful web seminars 2019 in collaboration with the European Network on Independent Living (ENIL). The first [webinar in May 2019](#) was held to introduce the activities of the DRD-network and to facilitate the exchange of information and experience between people with disabilities, organisations of people with disabilities, lawyers, legal professionals, legal students and others. The second [webinar in November 2019](#) focussed on "Law for accessibility". The theme of the webinar was how you use the law for better accessibility as a key to an inclusive society. We addressed a case from the Irish high court on the right to vote for blind people and discussed the access legislation – Americans with Disability Act (ADA) and European Accessibility Act (EAA). The webinars reached up towards 33 participants and were very successful. The rich discussions and the growing number of participants show that there is considerable interest in webinars as a method for discussions and dissemination of information.

Konkurrera med användbarhet och tillgänglighet (Compete with usability and accessibility)

Konkurrera med användbarhet och tillgänglighet – standardisering för att nå nya marknader/ökande marknadsandelar (Compete with usability and accessibility – Standardisation for new markets/increased market share) is a project owned by KTH that is realised together with Begripsam, Ergolab and Independent Living Institute. It aims to examine how accessibility and usability, as well as the use of standards, contribute to increased competition and which elements companies and other actors view as the basis to produce accessible and usable products and services. ILI contributes

by conducting interviews with relevant actors, disseminate an enquiry and analyse the material from human rights and sustainability perspective. The initial activities were carried out during 2019, and the project is planned to be completed in May 2020.

Assistanskoll

After the project period ended for [Assistanskoll](#) and its funding from Allmänna Arvsfonden ran out during 2010, the web-based service has continued to grow in content and reach. Assistanskoll provides information, facts and numbers, analysis and advice to assistance users, their families and personal assistants on, for example, choice of assistance provider. Assistanskoll keeps the public up to date with the legislative changes, the political game surrounding assistance, case law and market development. The number of assistance users had fallen with 2020 individuals since October 2015 when 16 179 persons received assistance allowance from the Swedish Social Insurance Agency. The number of assistance users is now down to the levels from 2007 (however, the number of individuals with personal assistance granted by their municipality has increased during the same period).

Assistanskoll is also a tool for municipal administrators when they must disseminate information and advice to assistance users and their families. At the end of 2019, 205 assistance providers participated in [Assistanskoll's comparison service](#) (201 private and four municipal). In addition, 39 assistance providers that have not provided information are listed. Assistanskoll's website had 762 000 page views during the year (849 000 during 2018 – a decline with 10% back to the 2017 level). This exposure makes Assistanskoll's website and newsletter an interesting forum also for advertisers who now cover almost all ongoing costs for Assistanskoll.

[Assistanskoll's newsletter](#), edited by Kenneth Westberg, is published approximately once a month and has achieved a market-leading position in monitoring the development within the field of personal assistance in Sweden. Our articles and other information is frequently quoted. The newsletter reaches 5 300 e-mail addresses. The target groups are assistance users, their relatives and personal assistants, assistance providers, disability organisations and their magazines, unions, LSS-administrators, authority 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 ["Work as an assistant"](#), ["Payment for personal assistance during inconvenient working hours"](#), ["What are personal assistants paid?"](#), ["Recruiting personal assistants"](#), ["Organising your own personal assistants"](#) and ["Preparing yourself for your assistance assessment"](#) has become very well-visited.

Assistanskoll also has a comprehensive page with statistics on the number granted personal assistance, new grants/denials, costs for assistance, and how many assistance users that have chosen private companies, municipalities, cooperative etcetera.

Examples of activities within Assistanskoll during the year:

- 111 news articles on personal assistance have been published on the website.
- Assistanskoll's journalist Erik Tillander visited the Almedalen week in June/July and made a series of reports from there.
- Two columnists, Nora Eklöv and Thomas Juneborg write regularly on Assistanskoll.
- Assistanskoll.se is a progressive web application- which means that it can be installed on mobile phones.

Other ongoing activities

The on-line library, PA-network, PA-tip and Fashion Freaks

[ILI:s online full-text library](#) offers authors publishing, exposure and secure archiving of, their work, such as articles in scientific journals, reports, manuals and lectures on Independent Living and related subjects. Presently, there are just over 600 documents in the searchable library, most of which are written in English, about 200 in Swedish and approximately 100 in other languages, mostly German, French and Spanish. We have, for example, a number of bibliographies such as those the British researcher M. Miles asked us to publicise on the treatment of persons with disabilities in Asian cultures.

The [PA-network](#) disseminates information on personal assistance in Sweden through articles and summary texts in English, as well as information on the situation for assistance users in other countries. We often receive appreciative comments from readers in different countries. The communication with the readers also includes providing advice based on the content of the articles.

[PA-tips](#) (personal assistance tips, formerly Assistanstips) is about gathering, documenting (by text and image, video or drawings) and disseminating tips, devices and examples that assistance users and their assistants have developed concerning different assistance situations. Allmänna Arvsfonden earlier funded the project. Its webpage is [patips.se](#).

[Fashion-Freaks – your dressing room on the internet](#) is about fashion, clothing and vanity from a seated perspective. Fashion Freaks' basic idea is that wheelchair users are as vain as others. We are all unique individuals with the right to personal taste and style. At the same time, it is almost impossible to find stylish clothes sewn for "seated" shapes. Fashion Freaks is a wardrobe filled with adapted basic patterns, sewing instructions, descriptions on how to adapt ready-made garments and much more – all fitted for wheelchair users. Fashion Freaks' webpage, which is available in both Swedish and English, earlier had project funding from Allmänna Arvsfonden and has continued a large number of visitors, approximately 400 visitors per day of which half is from Sweden.

Organising conferences/ seminars/ study-visits / educations as well as participating in other stakeholders' events

During the year, a number of conferences, seminars, study visits and educations were organised, as well as ILI's personnel participated in the events of other organisations/actors, such as:

- DRW has had several study-visits from organisations and municipalities during the year, for example, MISA, HRF, Haninge municipality, the Swedish Migration Agency, Syncentralen and ULOBA from Norway.
- DRW has participated in various events/seminars/conferences among others SRF Bransch Organisationer in Härnosand, Järvaveckan, MR-dagarna, Rinkeby hälsomässa and the half-time conference "Häslöfrämjande etablering" (health promoting establishment).
- DRW has had several different activities such as Vintermingel – open house, Seminar "Forum för lösningar", a course in photovoice, workshop at Rehab Station, education for Botkyrka and Salem municipalities.
- MLSV recorded videos at Uppsala university with Maria Chöler in January. These were disseminated as information on disability discrimination and what you can do if you have been subjected to this.

- MLSV arranged an open final seminar with interesting reflections for the future.
- 1/14 LSS-conference together with BOSSE and parliamentary politicians.
- 1/18 Visit from Simo Vehamas from Finland working at Stockholm University, Department of Special Education.
- 1/29 meeting with DO on a platform for information about active measures.
- 4/26 Start-up meeting for the project Article 19 as a tool. Representatives from the cooperative municipalities and organisations got information on article 19, the general comment and the project plan. Approximately 40 participants.
- 5/1 The European day for Independent Living – STIL and ILI – theme then EU elections.
- 5/20 DRD webinar, “Disability Rights Defenders”.
- 5/28 Study-visit from Belgian social enterprises and authorities.
- 7/1 Start-up meeting for the project “Konkurrera med användbarhet och tillgänglighet – Standardisering för att nå nya marknader/ökande marknadsandelar”.
- The Almedalen week:
 - 7/2 [“Hur kan artikel 19 stärka LSS?”](#). Cooperation between STIL, Unga Rörelsehindrade and ILI.
 - 7/3 “Hur säkerställs god etablering för migranter med normbrytande funktionalitet?”
 - 7/5 “Vägar mot ömsesidig integration – rättigheter för migranter med normbrytande funktionalitet”, launch of DRW’s information handbook and dialogue with GD Malin Ekman Aldén, MfD and others.
- 8/27 Study-visit RWI, Zimbabwe HR Capacity Development Program.
- 9/9-11 ILI and ENIL conference PA in Warsaw with ENIL’s network.
- 9/17 Participating at seminar I the Parliament organised by ICJ on “Program för Rättstaten Sverige 2019”.
- 10/1-4 ILI at the conference “Montenegro Network – The future of the Welfare State in the - Western Balkans”.
- 11/25 DRD webinar “Law for Accessibility”
- 12/3 “Respekt för rättigheter?” Seminar in the Parliament coordinated by Funktionsrätt Sverige. Launch of civil society’s report on Sweden’s implementation of the UN Convention of Rights for Persons with Disabilities. Followed by mingle at KFO and further dissemination.
- 12/9 [“Var finns tänderna?”](#) Article 19 in collaboration with the organisation MLSV. Document with initiated analysis of remedies connected to the convention and corresponding Swedish jurisprudence available.
- 12/12-19 DRW participated at a UNHCR conference in Geneva and was singled out as a good example.

Publications, interviews, stakeholder responses, and representation in various media

ILI’s staff published news articles, text, images and videos in various media during the year.

- 111 news articles on personal assistance have been published on Assistanskoll’s webpage.
- An in-depth essay on the foundations of article 19, CRPD was produced in collaboration between ILI and Susanne Berg on a commission by STIL.
- An education in practical discrimination law for STIL’s members has been offered to STIL. A follow-up will be done in 2020.
- DRW’s webpage was visited by 2 600 visitors on 4 000 visits during 2019. Six newsletters were published containing a total of 62 news articles, interviews, videos and event information.

- DRW was interviewed numerous times in the media.
- DRW's Facebook-page had 270 followers at the end of 2019.
- DRW's information handbook "[Vägar mot ömsesidig integration](#)" was published and launched during the Almedalen week.
- The webpage of Article 19/Law as a tool had 381 followers, the newsletter had 287 subscribers, and ten issues were published during the year (2 belonging to Law as a tool).
- DRD sent three newsletters during the year with short descriptions of legal cases, court decisions, law references, publications, reports and posts on events, teaching and funding opportunities, to more than 400 subscribers.

Stakeholder responses and political activities 2019:

- 1/15 [ILI comment on the Report from the Parliamentary Committee on LSS](#). The report has not been sent out for stakeholder consultation.
- 3/15 ILI stakeholder response on SOU 2018:70 "En arvsfond i takt med tiden".
- 3/29 ILI stakeholder response on MfD's translation of General comment number 5 regarding Article 19, CRPD followed by dialogue meeting during spring, consultative meeting in October 2019 and final version received in 2020.
- 5/3 ILI stakeholder response on Ds 20219:2 "Höjda åldersgränser i pensionssystemet och i andra trygghetssystem.
- 5/22 [ILI stakeholder response on Ds 20129:4](#) "Förslag till en nationell institution för mänskliga rättigheter".
- 9/12 ILI stakeholder response on MfD's Dnr 2019/0067, "Underlag till Tillgänglighetsnav"
- 11/29 [ILI stakeholder response](#) on SOU 20219:23, "Styrkraft i funktionshinderpolitiken".
- 12/3 Contributing to the Civil Society's shadow-report.
- 12/9 [ILI stakeholder response](#) on PM. "Personlig assistans för samtliga hjälpmoment som avser andning och måltider i form av sondmatning. Law proposal was stopped.

Collaboration with Föreningen Med lagen som verktyg (Law as a tool association)

[Föreningen Med lagen som verktyg \(The Law as a tool Association\)](#) was founded 2015 on the initiative of ILI and others but is run under its own direction as a member-based non-profit organisation. The association has the same name as ILI's earlier Arvsfond-project, Med lagen som verktyg. The association pursues cases of discrimination based on disability and if necessary litigates. In addition, the association provides information on civil and human rights for persons with disability, advice and information about discrimination based on disability. ILI has provided administrative support to the association during the year.

The Law as a tool association had six cases sued in court during 2018 and examined a further ten cases. Activities 2019 has focused on pursuing these and finding new administrative forms for a sustainable organisation, in lieu of ILI's project Law as a tool is completed.

The association's yearly assembly was held on the 19th of April. The 9th December, the association organised the seminar "[Var finns tänderna?](#)" in collaboration with Article 19 as a tool.

Ongoing legal cases:

- No bus stop announcements on buses in Örebro, ongoing problems despite earlier conciliation.
- Discrimination against students with dyslexia in the national tests.
- Lack of accessibility to pay-at-the-pump machines at automated petrol stations.

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

Collaboration with the disability movement in Sweden and internationally as well as other professional contacts

Through our long, joint work with other organisations to expand and defend our civil rights and increase our concrete opportunities to live as others, ILI has built useful contacts in our area within the Swedish civil society. Within this broad network, we have easily been able to find co-applicants for project applications and for other types of cooperation. We also have useful international contacts through our long-standing 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 experiences.

ILI has over the years, become an international information and contact hub, which has helped us expand our network and deepen our cooperation with other organisations. In this way, we have together with other actors been able to contribute to an increased pace of development in the area of disability within a number of countries concerning policy for accessibility, personal, assistance, technical aids and employment. The subjects can deal with projects, literary sources, contact mediation with other organisations and experts, or concern individuals who need support and advice.

During the year, ILI's chair and director were:

Adolf Ratzka:

- Member of the Editorial Board ("Overseas Editor") and "peer reviewer" for the magazine ("[Disability and Society](#)") "Disability and Society", UK.
- Member of the International Advisory Council, Ecoplan.
- Board membership of [Stiftelsen till Rolf Bergfors minne](#) (Foundation in Memory of Rolf Bergfors).

Jamie Bolling:

- Co-chair of ENIL ([European Network on Independent Living](#)), member of ENIL's, Management Team and Audit Committee.
- Board member in [Bente Skansgårds Independent Living Fond](#).
- Member of [STIL](#)'s board.
- Vice Chairman of [MyRight](#)'s Board.

ILI staff

Among our personnel, there is a wide variety of competence and experiences, many with experience of living with a disability, a good gender balance and age span and coming from a multitude of different countries. During 2019, ILI's staff has consisted of the following individuals, most of whom have worked part-time, some only during shorter periods:

Adolf Ratzka, ILI's founder, chair of the board and project co-worker for Disability Rights Defenders and Disabled Refugees Welcome.

Algren Morgan, project co-worker for Assistanskoll, Med lagen som verktyg and Disabled Refugees Welcome.

Caroline van Mourik, project co-worker Med lagen som verktyg until February.

Emil Erdtman, journalist and project leader for Med lagen som verktyg until April.

Erik Tillander, journalist and project co-worker for Assistanskoll and Artikel 19 som verktyg.

Gabriel Boulos, lawyer and project co-worker for Disabled Refugees Welcome, until October.

Jamie Bolling, director and project leader for Disabled Refugees Welcome and project co-worker for Artikel 19 som verktyg.

Julius Mvenyi Ntobuah, field worker for project Disabled Refugees Welcome.

Kenneth Westberg, journalist and project leader for Assistanskoll.

Linda Robertsson, office manager, including administration, personnel and economy.

Maria Åkesson, support worker for Disabled Refugees Welcome until September.

Mari Siilsalu, project co-worker for Artikel 19 som verktyg, from September.

Ola Linder, lawyer. Project leader for Artikel 19 som verktyg and project co-worker for Med lagen som verktyg and Disabled Refugees Welcome (until August).

Philip Day, webmaster, programmer, co-worker for Assistanskoll, Med lagen som verktyg/Anmälningstjänsten and Artikel 19 som verktyg.

Rahel Abebaw Atnafu, field worker and administrator for Disabled Refugees Welcome.

Riitta-Leena Karlsson, project co-worker for Disabled Refugees Welcome.

Selina Grieser, project co-worker for Disability Rights Defenders and support worker for Disabled Refugees Welcome.

Sooz Romero Orellana, communicator and method developer for Disabled Refugees Welcome.

During the year, the following individuals have done internships at ILI:

Annemarie Isbert, ERASMUS-fellow with contributions mostly for Disability Rights Defenders, two months.

Alex Caputo Janhager, with contributions for Artikel 19 som verktyg, 5 weeks.

Brooke Antol, with contributions for Disabled Refugees Welcome, seven weeks.

Caitlyn Thurber, with contributions for Disabled Refugees Welcome, seven weeks.

Dilek Hakbilen, with contributions for Disabled Refugees Welcome, five months.

Margaret Muru, with contributions for Disabled Refugees Welcome, five weeks.

In addition, work has been conducted on a consultancy basis and through short specific contacts/freelance assignments. Consultative assignments for more extended periods were carried out by:

Anna Bruce, Raoul Wallenberg Institute, with contributions for Artikel 19 som verktyg.

Elena Quiñonez, accountancy services.

Susanne Berg, text production and translation assignments.

Suzanne Elmqvist, with contributions for Artikel 19 som verktyg.

Doro Riedel, with DRW photovoice contributions.

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- [Allmänna Arvsfonden](#) (Swedish Heritage Fund) that funded the projects Artikel 19 som verktyg, Disabled Refugees Welcome och Lagen som verktyg.
- [Bente Skansgårds Independent Living Fund](#) that contributed project funding to Disability Rights Defenders and participation in ENIL freedom Drive 2029.
- [Hultmans Stiftelse för Forskning och Bistånd](#) that contributed funding to ILI's activities.
- [STIL/ILU](#), Stiftarna av Independent Living i Sverige that contributed funding to ILI's activities as well as project funding for an in-depth essay on the foundations of article 19, CRPD and education in practical discrimination law for STIL's members.
- [Vinnova](#) that funded the project Konkurrera med användbarhet och tillgänglighet, where ILI is 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 [STIL](#) and its chairperson until 1995; ENIL's first chairperson 1989-1992; together with Rolf Bergfors, founded [GIL](#) and [Independent Living Institute](#) and was 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 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, chairperson of [ENIL](#), the European Network on Independent Living; founder and director of the [Center for Independent Living, Sofia](#).

Miro Griffith, 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 2019, the board held two board meetings, the 15th April and the 3rd November, both in the form of conference calls via telephone. In addition, contact has been made through email, telephone and individual meetings.

Stockholm, 2020 -

Adolf Ratzka

Bengt Elmèn

Jamie Bolling

Judith Heumann

Kapka Panayotova

Miro Griffith