

## Annual Report 2017

Independent Living Institute (ILI) works to promote opportunities for disabled people to more personal and political power, self-determination, full participation and equality through information, education, impact work and project activities.

During 2017 ILI worked through several projects to reach its goals and visions described in this document. All the projects have their own webpage, facebook page and disseminate newsletters.

### Project Activities

#### The Law as a Tool for Social Change

The Law tool as a tool works to increase the legal capacity in the disability movement in Sweden by gathering expertise, educating stakeholders and defending human rights for people with disabilities. The project was initiated by Independent Living Institute together with Swedish Disability Federation, Applied Human Rights, the cooperation for personal assistance STIL and the DPO:s DHR and RTP. The project is financed by the Swedish Inheritance Fund. The broader purpose of the project is to ensure that the rights of people with disabilities are better implemented by using the law and case-law as tools against individual and structural discrimination. Close collaboration is conducted with the Swedish Disability Federation's project "From Talk to Action" (which focuses on implementation of the rights under UN Convention on the Rights of Persons with Disabilities (CRPD)) and with the non-profit association "With the law as a tool" that takes members' legal cases - to court if necessary – with the support from a network of lawyers that sometimes take cases pro bono.

The project publishes information on discrimination law, interviews with human rights lawyers and university papers in the field of accessibility and discrimination and in-depth analysis of different issues regarding discrimination on the grounds of disability, primarily on the website <https://lagensomverktyg.se/>. The website had 12,000 visits and 21,000 page views, the Facebook page 205 followers and the Twitter account 226 followers. The newsletter had 206 subscribers and nine numbers were sent during the year. The project has been featured in several magazines on law and disability. A debate article on lack of access to justice and proposal for improvements was published in Dagens juridik together with the Disability Federation of Sweden, Lika Unika, RFSL, Malmö Against Discrimination and Gothenburg's Human Rights Center.

Several seminars were held in 2017. On June 2, lawyer Hanna Gerdes led a course on discrimination law and how to write complaints and on March 28, the project's lawyer Ola Linder led a workshop at a conference on housing discrimination. On May 13 he held a workshop on the Asthma and Allergy Association and on November 18, the project held a lecture in Gothenburg for Sweden's guide dog users. Many reports of discrimination of guide dog users come to ILI's Disability Ombudsman Reporting Service [anmalningstjansten.se](http://anmalningstjansten.se) and a thorough analysis has thus been made of their legal situation.

The project participated in the Swedish summer week of politics in Almedalen, Gotland and organised on July 4th a lunch seminar and five shorter hearings. The project also had a seminar at the first summer school on disability rights in Sweden, August 25, organiser by the project From Talk to Action. Another collaboration with the project From Talk to Action was a training tour initiated by the Swedish Agency for Participation to inform and educate about the CRPD. Sweden's 16 anti-discrimination bureaus (civil society organisations working against discrimination on all grounds, partly funded by the state) were contacted and offered a half-day training, which was conducted in Stockholm, Örebro, Malmö and Gothenburg. A similar seminar aimed for local disability associations was held in Örebro, Stockholm, Luleå and Umeå. The project trainee lawyer Maria Chöler wrote short stories to explain the CRPD's first 30 articles. These were then printed by the Authority for Participation, that also produced an information film in which Ola Linder participated, explained the role of the CRPD in the Swedish legal context.

The law as a tool has written about and analyzed several legal processes, like:

- DO - Discrimination Ombudsman against Vara municipality: The project was in place at the main hearing in Skaraborg District Court on May 3 and analyzed the verdict.
- DHR - Swedish Mobility Impairment Organisation vs. Region Gävleborg: The case got a test permit in the Supreme Court on May 8 and a decision on December 21 that DHR had sued the proper counterpart.
- DO against Södertörn: The law as a tool were present at the main hearing in the Labor Court on August 30, and wrote an analysis of the verdict on October 11th and published an comment from Richard Sahlin.
- Anders against Lekeberg municipality: This cases was about the right to independently choose where to live and was won in the administrative court of Gothenburg, referring to European convention of human rights.

The Law as a tool also analyzes cases concluded by DO, for example, about lack of IT accessibility at universities, and settlements about lack of accessibility for guide dog users and lack of IT accessibility for employed at the authority of insurance (Försäkringskassan).

The LinkedIn group Disability Rights Defenders has been launched for international networking. [Information in English about the project](#) (se IDRDN below).

## **The Disability Discrimination Reporting Service (Anmälningstjänsten)**

[Anmälningstjänsten](#) helps individuals and organizations to report cases of discrimination to the [Equality Ombudsman](#) and, where appropriate, the respective municipal building authority. The service uses a number of pre-formulated options on the website, which one chooses with a click, and the reported discrimination cases are documented in a Google-searchable public database. To date over 3 400 discrimination cases have been reported this way.

The technics of the web have been updated to function on small screens. Information has been updated both from language wise and legal wise. Reporting has increased with 45 incidents reported during 2017. A facebook ad was spread and a flyer published in braille, which has been highly appreciated. There were 5000 site visitor and viewing of 14 500 pages.

## **PA-tips**

[PA-tips](#) (Personal Assistance tips) a former Allmänna Arvsfonden project which finished in december 2015 has continued on a smaller scale. From May - December 2017 PA-tips was financed by [Petrus och Augusta Hedlunds stiftelse](#). Through the project there is a promotion of user driven assistance. ILI has cooperated with ZSL/RMI Bad Kreuznach in Germany where a similar project is being carried out.

The project gathers, documents and spreads tips by pictures and text, videos and drawings. Tips are examples that can be used by assistance users in organising own assistance. The tips have been developed by both assistance users and assistants. The tips are knowledge on how to best promote opportunity for disabled people to live active and well-functioning lives with personal assistance as well as increasing self-determination.

According to the Independent Living movement, people with disabilities are the best experts on their needs and should therefore learn from and help each other to change their situation. By becoming a more informed and better supervisor for their assistants, assistance users can improve their personal assistance and increase their possibilities for self-determination in daily life. This requires, among other things, experience and knowledge of practical and organizational solutions, such as the ways in which assistants can assist in particular situations. The idea is not to show "the best" solution for assisting users - we are not a homogeneous group but individuals with unique conditions, needs and preferences – but to suggest several solutions that assistance users can test and be inspired by in developing their own approaches. Assistance Tips encourages assistance users, their relatives and assistants as well as professionals involved in assistance to improve service quality and assistants' working environment. The project's website is [patips.se](http://patips.se) and can also be found at Facebook [facebook.com/PersonligAssistansTips/](https://facebook.com/PersonligAssistansTips/).

During 2017 PA-tips has noticed a difference in atmosphere for persons living as assistance users. There is a difference caused by the questioning of the legislation for assistance which has created an uncertainty among users. People do not dare give tips describing their assistance afraid of consequences. More individuals than before choose to be anonymous and others say no to the offer to give a tip. Many people have lost their assistance during the year or had a decrease in hours of assistance. This has given rise to fear of losing more hours if they talk about their assistance. Many are afraid and have been so involved in combating for their assistance that they have no energy left to speak about their situation. This has led to the project giving advice through individual telephone conversations.

## **Disabled Refugees Welcome (DRW)**

[Disabled Refugees Welcome](#) is a new three year integration project carried out by the Independent Living Institute. The project is financed by Allmänna arvsfonden. The purpose of DRW is to develop new methods to better the conditions of the receiving and integration of disabled newcomers. During the project the target group's needs will be documented and activities developed that can be incorporated in the natural migration process.

DRW started in September 2017 with 10 employees all from different countries. Julius Ntobauh who had the idea of the project along with Adolf Ratzka are both employed within the project. Until december 2017 the project team began the work through different methods in order to reach the project goal of having a society with equal opportunities for a life with Independent Living no matter the function capacity or number of years in Sweden. The webpage and social media channels were

created. Material has been produced in different languages and spread through OutReach activities. A database for contacts has been created and is continually updated. A reporting system is in place for the control of the project results. Ten case studies have been completed with the target group of newcomers. DRW had one intern, himself a newcomer during a six week period who contributed to one interview and translated materials. The project has been interviewed two times.

DRW in the social media:

- [Facebook-sida](#) open on the 7th of November 2017: the number of followers on the 31st of december 2017 was 84.
- The number of people reached during the first two months was 2050 facebook users.
- The webpage was launched on the 10th of december 2017.

## **International Disability Rights Defenders Network (IDRDN)**

The project "International Disability Rights Defenders Network" started December 1, 2017. The main goal of the project is to build an international network where information can be spread on how countries can use the law as a tool to better the life situations of disabled people. Information on cases and events in this area, for examples conferences, theme days and such are acknowledged and spread.

Information is spread through the newsletter that is sent to lawyers, legal students and teachers, state and local authorities and other key stakeholders working for the rights of disabled people. The first invitation was sent to potential members and over 200 have become members of the network. The work with the newsletter continues as well as the recruitment of new members to the network.

## **Assistanskoll**

[Assistanskoll](#) has continued to grow in content, scope and reach after the project funding from the General Heritage Fund ended in 2010. Assistanskoll provides information, facts and numbers, analyzes and advice to assistance users, their families and assistants in the selection of assistance providers. Assistanskoll keeps the public up to date on the rapid changes that take place in legislation, case law and market development.

Assistanskoll this year has had an important role in the LSS debate. The project has been of influence through interviews with key people and contributed to the stopping of reassessments for personal assistance which were resulting in the loss of assistance for users. The Government is now bringing forth a new legislative proposal.

Assistanskoll is also a tool for municipal administrators to disseminate information and advice to assistance users and their families. By the end of 2017, 219 non-municipal assistance providers participated in [Assistanskoll's](#) comparative service. These providers claimed to have a total of 11,313 customers / members and represent about 75% of the Swedish private assistance market. [Assistanskoll's](#) website had about 809,000 page views during the year (686,000 in 2016 - an increase of 18%) and 400,000 visits. This exposure makes the Assistanskoll website and newsletters an interesting forum also for advertisers who now cover almost all Assistanskolls ongoing costs.

[Assistanskoll's](#) newsletter, edited by Kenneth Westberg, is published once a month and has achieved a market leading position in the surveillance of the development of personal assistance in Sweden. Our articles and other information are often quoted. The newsletter reaches 6,500 e-mail addresses, many of which are assistance providers and LSS administrators. Other subscribers are assistance users, their

relatives and assistants, disability organizations and their journals, unions, 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 för personal assistance in inconvenient working time", "What are Personal Assistants paid?", "Recruiting Personal Assistants", "Organizing Your Own Assistance" and "Preparing Yourself for Your Assistance Assessment" have become very popular.

Assistanskoll also has a comprehensive page of [statistics](#) on, for example, the Swedish Social Insurance Agency's reassessments, costs of personal assistance and how many assistance users that have chosen private companies, municipalities, cooperatives etc.

Examples of what happened within Assistanskoll during the year:

- 140 news articles on personal assistance have been published on the website.
- Assistant journalist Erik Tillander visited Almedalen in June / July and made a series of reports.
- Municipal assistance providers can now participate in the comparative service, Grums, Uppsala and Täby municipality participate in the comparison.
- On the sites ad page , you can search the Employment Services job listings for personal assistants. Assistance providers, municipalities or others can also post job ads on Assistanskoll.

## Other ongoing activities

### The on-line library and PA-network

[ILL:s online full-text library](#) still 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 available in the searchable library are over 600 documents, most of which are written in English, about 200 in Swedish and 100 in other languages, mostly German, French and Spanish. We have, for example, a number of bibliographies which British social scientist M. Miles asked us to publish, among other themes, on the responses to disability in Asian cultures. [PA-network](#) disseminate personal assistance information in Sweden through articles and summary texts in English, as well as information on the situation of personal assistance users in other countries. We often receive appreciative comments from readers in different countries and the correspondence with the readers also include giving advice on the topics of the articles.

### Conferences/ seminars/ trainings as well as participation in other stakeholders events

During the year ILL organized a number of conferences, seminars and trainings. ILL:s personnel also participated in other stakeholders events. Here given are many of the activities:

- 6/3 Ola Linder and Paul Lappalainen participated in a [roundtable](#) on implementing the UN CRPD at the Raoul Wallenberg Institute in Lund.
- 27/3 - 28/3 2017: Julius Ntobauh och Maria Chöler participated in a course held in Trier Germany on Legislation for disability and implementing the UN CRPD.
- 28/3: Ola Linder held a workshop at a [conference on living arrangements and discrimination](#).
- 21/4: Training for Equal Rights Offices in Stockholm South and Uppsala.

- 13/5. Ola Linder held a workshop on discrimination legislation for the Astma- and allergy association national meeting.
- 29/5 : Training for the Örebro Rights Center, Rights Center i Dalarna, Anti-discrimination Bureau i Östergötland and the Discriminations Bureau Humanitas in Eskilstuna/Västerås
- 29/5: Seminar for civil society in cooperation with the Rights Center in Örebro
- 2/6: Hanna Gerdes led the training Disability Discrimination Reporting – [Know the Discrimination legislation?](#)
- 4/7: In [Almedalen](#) a successful lunch seminar was held with five key persons being questioned on the changes in the Swedish discrimination legislation with among other Morten Kjaerum from the Raoul Wallenberg Institute and Hanna Gerdes .
- 25/8: Seminar on the UN CRPD and discrimination legislation in cooperation during the summer school of Från snack till verkstads on disability and Human Rights.
- 3/10 ILI participated in the Swedish disability movements meeting with the Council of Europe’s Human Rights Commissioner Nils Muižnieks.
- 4/10: Training for Malmö against discrimination and ADB Helsingborg
- 18/10: Seminar for the civil society in cooperation with the ADB Uppsala.
- 19/10: Maria Chöler participated and wrote an article on the conference on cooperation on accessibility [in Uppsala](#).
- 24/10: Information stand at the Human Rights Day in Trollhättan
- 25/10: Training for Gothenburg Rights Center and ADB Trollhättan
- 10/11: Seminar It’s time for us have rights - but how? [”Det är dags att få rätt! Men hur gör vi?”](#) during Human Right - Days led by Susanne Berg.
- 18/11: Ola Linder and Maria Chöler gave a lecture at in Gothenburg on [discrimination and rights for guide dog owners](#)
- 21/11 Seminar for civil society in cooperation with Norrbottens Rights Center
- 22/11 Seminar for civil society in cooperation with Västerbottens Rights Center

## **Publications, interviews, referrals and representation in various media**

During 2017 ILI published articles and other materials in the media.

- On [Assistanskoll](#)s website there were 140 news articles on personal assistance.
- On [Lagen som verktyg’s](#) - Using the law as a Tool website : Interviews were published with the following legal experts: [Annika Jyrwall Åkerberg](#), Hanna Gerdes, [Anna Bruce](#), Laura Carlson, [Kerstin Burman](#) och Andreas Pettersson. Papers were published on [deficient accessibility and higher education, right to independence in the UN CRPD](#) and [deficient accessibility in primary school](#). Jennifer Jungelin wrote on [The view of youth on discrimination](#). A debate response was published by the legal expert Richard Sahlin on [discrimination and wage subsidy](#). The webpage for Using the law as a tool - <https://lagensomverktyg.se/> had 12000 visits in 2017 with 21 000 page showings. The traffic comes mostly from Facebook. The Facebook site for Using the Law as a Tool has 205 followers and the Twitter account 226 followers. [The Newsletter](#) had 206 subscriber and had nine numbers during the year.
- Using the law as a tool responded to the legal proposition 2016/17:220 on taking away the exception of small companies from the discrimination legislation.

- Together with STIL ILI responded with a [referral](#) on the proposition on the förslagen i utredningen Bättre skydd mot diskriminering (SOU 2016:87).
- The project contributed with its expertise in the Swedish Disability Movement's response [for the UN High Commission on article 13](#) on the accessibility of the legal system.
- The project gave comments on the UN Committee's General Comment on article 19 and article 5, as well as contributing to translation for Sweden on article 3 and 4.
- Emil Erdtman and Ola Linder were interviewed in both Lag & avtal 2/2017, Liv nr 3/2017 and [Läs&skriv nr 4/2017](#).
- A [debate article](#) was published on the October 6 in Dagens juridik along with Funktionsrätt Sweden, Lika unika, RFSL, Malmö mot diskriminering and Göteborgs rättighetscenter.

## Study Visits at ILI

During the year ILI received the following study visits:

- 9/2: study visit from Japan on De-institutionalization and Personal Assistance (AR + STIL and others)
- 4/7/2017: Miro Griffiths a PHD student with Manchester University visited ILI and spoke with Adolf Ratzka on the future development of Independent Living.
- 1/9/2017: I-Living from Greece visited ILI with a group of persons. Interested in IL and personal assistance in Sweden.

## Föreningen Med lagen som verktyg - Association of Using the law as a tool for social change

Föreningen Med lagen som verktyg, a non-profit organisation was started in 2015 through the initiative of among others ILI and is driven in its own regime based on a membership. The association has the same name as the project with their activities complementing one another. The association takes on members discrimination cases and if necessary to the court. On top of this the association raises awareness on the rights of disabled people, gives advice and information on discrimination based on disability. ILI has during the year contributed to the administration support of the association.

The association has during the year discussed cases at the board meetings and member meetings. Twelve cases were activated, with at least one being driven with a lawyer pro bono. The association has also contributed to a rights action on dyslexia discrimination during a national exam. The association is continually analysing cases and doing trainings on the various cases.

As the association needs to develop and expand once the project has finished a conference on financing was held on May 12 with lawyers and representatives from various DPOs. A proposal for an independent Rights Centrum was laid forth that would work with cases as well as training.

## Collaboration with the disability movement in Sweden and internationally, and other professional contacts

In our joint work with other organizations for defending our rights as citizens and improving the concrete possibilities for living equal to others, ILI has built up good contacts with Swedish civil society



in our field. With the help of this wide network we have easily found collaborators for grant applications and other work. We also enjoy good international contacts due to our early involvement in the international Independent Living movement within Disabled People's International and ENIL, the European Network on Independent Living, as well as through frequent mutual visits and numerous joint projects.

Over the years ILI has developed into an information and contact referral hub which has allowed us to widen our network, deepen our cooperation with other organizations and to contribute to an increased rate of change in a number of countries regarding policy for accessibility, personal assistance, assistive technology, and employment. Inquiries may involve projects, literature sources, referral to other organizations, resource persons or may assist individuals looking for support and advice.

During the year ILI staff members have served as:

**Adolf Ratzka:**

- Member of the Editorial Board ( "Overseas Editor") and "peer reviewer" for magazine ("[Disability and Society](#)") "Disability and Society", UK.
- Distinguished Fellow and "peer reviewer" for the magazine "[The Review of Disabilities Studies](#)", Center on Disability Studies, University of Hawaii.
- Member of the International Advisory Council, Ecoplan.
- Board membership of [Stiftelsen till Rolf Bergfors minne](#) (Foundation in Memory of Rolf Bergfors).
- Board membership of [Access Sweden](#).
- Chairperson of the [non-profit membership association MLSV "With the law as a tool"](#).

**Jamie Bolling:**

- ENIL director until October 2017 and ENIL Senior adviser from October 2017 ([European Network on Independent Living](#))
- Member in ENILs Management Team and Audit Committee.
- Board member in [Bente Skansgårds Independent Living Fond](#).
- Vice President in [STILs](#) board.
- Election committee member [Swedish United Nations Association](#)

**ILI staff**

On the ILI staff there is a large variation of competences and knowledge, many with their own experience of disability, a good gender and age division as in foreign countries. Many have been working part time and some only during short periods:

**Adolf Ratzka**, director until October 2017 and an employee of the project Disabled Refugees Welcome.

**Algren Morgan**, project co-worker for Assistanskoll and the Law as a Tool.

**Caroline van Mourik**, project co-worker for the Law as a Tool and administration from July 2016.

**Emil Erdtman**, journalist and project leader for the Law as a Tool, from March 2017.

**Erik Tillander**, journalist and project co-worker for Assistanskoll.



**Jamie Bolling**, ILI director from October 2017 and project leader for Disabled Refugees Welcome.

**Johanna Andersson**, project leader for PA-tips.

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

**Kenneth Westberg**, journalist and project leader for Assistanskoll.

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

**Maria Chöler**, lawyer and co-worker project the law as a tool, and co-worker in the project IDRDN.

**Ola Linder**, lawyer and project co-worker for the Law as a Tool.

**Paul Lappalainen**, lawyer and project leader for the Law as a Tool until February 2017.

**Philip Day**, webmaster, database programmer, project co-worker for Assistanskoll, PA-tips and the Law as a Tool/the Disability Discrimination Reporting Service and project co-worker for Disabled Refugees Welcome.

**Rahel Abebaw Atnafu**, field work and administrator for the project Disabled Refugees Welcome.

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

**Samvel Atabekyan**, kommunikation Officer for the project Disabled Refugees Welcome.

**Sooz Romero Orellana**, field work coordinator and method developer for the project Disabled Refugees Welcome.

The following persons worked as consultants or as interns:

**Elena Quiñonez** and **Sebastian Ferrer**, support for finances.

**Maria Chöler**, intern for the law as a tool in the spring.

**Paul Lappalainen**, lawyer and consult during July - December for the law as a tool.

**Selina Griesser**, PHD student.

## Funding

### With thanks to:

- [STIL/ILU](#), founders of Independent Living in Sweden, contributed to ILI's operations through financial support.
- Allmänna Arvsfonden ([Swedish Inheritance Fund](#)) funded the project [the Law as a Tool](#) and [Disabled Refugees Welcome](#).
- [Petrus & Augusta Hedlunds stiftelse](#) funded the project [PA-tips](#).
- [Bente Skansgårds Independent Living Fund](#) financed IDRDN and the preparation of the 2018 May conference.
- In addition, ILI's activities were funded by banner advertisements on [Assistanskoll.se](#).

## Board composition and board meetings

**Adolf Ratzka**, Stockholm, in 1983 imported the Independent Living philosophy to Scandinavia, founder of [STIL](#) and its chairperson until 1995, [ENIL](#)'s first chairperson from 1989 - 1992, founded with the late Rolf Bergfors, [GIL](#) the [Independent Living Institute](#) and was the director from 1993 to October 2017.

**Bengt Elmén**, Stockholm, author, debater and lecturer, board member of STIL, Office Manager STIL 1987 - 1991.

**Gunilla Andersson** - substitute for Bengt Elmén, board member of STIL since 2006 and its vice president since 2016, president of the Rheumatism Association Lidigö since 2016.

**Jamie Bolling**, Härnösand, human rights defender focusing on disability issues, former member of the Swedish Green Party's national board, vice-chairperson of [STIL](#), PhD student, Former Director of [ENIL](#).

**Judith E. Heumann**, Washington DC, USA. [Judy Heumann](#) is 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; [World Bank Group](#) first Advisor on Disability and Development 2002-2006; Director, Department of Disability Services, District of Columbia; Special Advisor on Disability Rights for the US State Department 2010–2017.

**Kalle Könkkölä**, Helsinki, Finland, director of [Threshold](#), the first European Independent Living Center which he founded in 1973, co-founder of the Finnish Green Party, former Finnish MP, former chairman of [Disabled People's International](#), founder and president of [Abilis Foundation](#) etc.

**Kapka Panayotova**, Sofia, Bulgaria, chairperson of [ENIL](#), European Network on Independent Living, founder and director of the [Center for Independent Living, Sofia](#).

During the year the Board held two ordinary Board meetings, one via Skype on May 28 2017 and one through email with a per capsulam decision on December 10 2017. During the year there was regular contact with board members via email and telephone.

### Stockholm, 2018 -

Adolf Ratzka

Bengt Elmén

Jamie Bolling

Judith E. Heumann

Kalle Könkkölä

Kapka Panayotova