

ANNUAL REPORT 2016

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.

Projects

The Law as a Tool (Lagen som verktyg)

The project [The Law as a Tool](#) started its activities according to its final project plan. Co-applicants are [Handikappförbunden HSO](#), [Apply Human Rights, DHR, STIL](#), and [Personskadeförbundet RTP](#). A meeting with the co-applicants was held on September 21. The project also has a reference group consisting of representatives from MFD (the Swedish Agency for Participation), disability- and human rights organisations and legal experts on disability discrimination. In March 2016 Paul Lappalainen was employed as Project leader and Emil Erdtman was employed in May as communications officer. Caroline van Mourik started in July as information officer/adviser and the lawyer Ola Linder started in October.

The project shall improve the disability movement's access to legal expertise when it comes to education, defence and development of human rights of persons with disabilities in practise. The purpose is to ensure that the rights of persons with disabilities are strengthened by using the law and case-law as tools against negative and structural discrimination. During the year the project collaborated with the non-profit membership association ["With the Law as a Tool \(MLSV\)"](#) that handles legal cases, if necessary presenting them to court with the assistance of *Rättsnätverket* (the Rights Network, a lawyer's network).

During the year, the website of the association MLSV was merged with that of the project, [lagensomverktyg.se](#) (only in Swedish). The work to build a knowledge bank, including interviews, judgments, and support for filing discrimination complaints, was started. 15 articles, some in depth, were published. A monthly newsletter was established, which had 115 subscribers at the end of the year. Much work was dedicated to gathering relevant send lists.

The project focused on the law concerning deficient accessibility as a form of discrimination and the role of civil society in strategic litigation. Ola Linder wrote a legal brief on deficient accessibility as a form of discrimination, and the project produced a document on strategic litigation. The cases of the association MLSV, including the case regarding accessibility at the Royal Palace of Stockholm, and other cases, such as the DHR case concerning inaccessibility in collective transportation, was closely reported on the website. A debate article written by Paul Lappalainen and Ola Linder on November 21 in *Dagens Juridik* (The Law Daily) was widely spread and gained much attention.

Some of the conferences the project participated in are the following: 19 may "The CRPD and the law as a tool" together with the Swedish Disability Federation. Paul Lappalainen was in a panel in Almedalen (Sweden's largest political forum) and the Fundamental Rights Forum. Emil Erdtman and Caroline van Mourik participated in the Swedish Disability Federation's conference "The disability movement is mobilising" on October 18, and the course "With the Law as a Tool" in Borlänge October 21-22. Further, all co-workers in the project participated in a seminar (including panel and moderator) during Human Rights Days (MR-Dagarna) in Malmö, November 17-19.

A milestone activity was an international conference and seminars 24-25 November, with 51 and 41 participants respectively. Sid Wolinsky and Pat Kirkpatrick, from Disability Rights Advocates

in the United States, were keynote speakers. Professor Gerard Quinn contributed to the academic programme of the conference through a pre-recorded video. Professor Lars Trägårdh participated, amongst other academics. The event was organized in cooperation with KFO (The Co-operative Employers' Association) and Ersta Sköndal högskola. The was filmed and is available with subtitles on the website and Youtube.

A good foundation was laid for the further work of the project.

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. *Anmälningstjänsten* did not have particular funding during the year but will later on form an important part of the Law as a tool project (see above) once it has been updated and adapted to the project's needs.

PA-tips / Personal Assistance Tips

PA-tips was previously financed by the Swedish Inheritance Fund. These particular project activities ended in December 2015 and during 2016 similar activities proceeded in a smaller scale. From May to December 2016 the project had funding from Petrus & Augusta Hedlunds stiftelse.

PA-tips collect, document (by text, photos, video or drawings) and spread tips, tricks and examples that assistance users and their assistants have developed for many assistance situations. It is about knowledge that promotes the possibilities of people with disabilities to live an active and well-functioning life with personal assistance as well as increased 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 www.patips.se and can also be found at Facebook www.facebook.com/pages/PA-tips/521198964597578.

The project has several connections to Assistanskoll (see below) and during the year efforts have been put in to furthermore connect the two projects and develop its activities, for example the promotion of the model of direct employment by personal assistance users. To that aim two guides were produced: Anordna din egen assistans (how to organize your own assistance) and Att rekrytera personliga assistenter (how to recruit personal assistants), currently only published in Swedish. These are presented together with previously produced guides and articles in that same field, and some educational seminars were arranged. The model of direct employment by personal assistance users was the topic of a joint experience exchange during 2016 with ZSL/RMI Bad Kreuznach in Germany.

Disabled Refugees Welcome

In 2016 work has been put into the formulation and anchoring of the application for Disabled Refugees Welcome. The application was presented to the Swedish Inheritance Fund in April, which subsequently was revised a couple of times. In this preparatory work ILI's intern played a significant role anchoring of the application for Disabled Refugees Welcome. The application was presented to the General Heritage Fund in April, which has subsequently been revised a couple

of times. In this preparatory work, ILL's trainee played a significant role given that he is himself a recently arrived asylum seeker with disability.

Other on-going activities

Assistanskoll / Personal Assistance Watch

After [Assistanskoll's](#) project period and funding by the Swedish Inheritance Fund, in 2010, the web service has continued to grow in content and scope. *Assistanskoll* provides information, facts and statistics, analysis and advice to assistance users, their families and assistants in the choice of assistance providers. *Assistanskoll* keeps the public informed about the rapid changes taking place in legislation, case law and market development.

Assistanskoll is also used by municipal officers in informing and advising personal assistance users and their families. At the end of 2016, 243 non-municipal assistance providers were listed in [Assistanskoll's](#) comparison service. These providers reported a total of 11,174 customers / members which represents approximately 88% of the Swedish private personal assistance market. The [Assistanskoll](#) website received about 686,000 page views during the year (499 000 in 2015 - an increase of 37%). This exposure makes [Assistanskoll's](#) website and newsletter an interesting platform for banner advertisements which cover almost all of its running costs.

[Assistanskoll's](#) newsletter, edited by Kenneth Westberg and published about once per month, is a leader in monitoring personal assistance developments in Sweden. Our articles and information are often cited. The newsletter is distributed to 6,500 email addresses, many of whom belong to assistance providers and public administrators. Other subscribers are assistance users, their relatives and assistants, disability organizations and their magazines, trade unions, public authorities and politicians at all levels.

There is a particularly growing interest for some of the website's information sections and guides such as the comparison of [Trade union collective agreements](#), the guides [working as a personal assistant](#), [Unsocial hours compensation for personal assistants for a specific time and date according to trade union agreements](#), [What are the personal assistants' salaries?](#) and [Prepare for your assistance assessment](#).

Assistanskoll also compiles current [statistics](#) such as the results of the Social Insurance Fund's bi-annual reassessments, personal assistance costs to the State, and the number of assistance users that have chosen private companies, municipalities, cooperatives as service providers.

Examples of what happened on [Assistanskoll](#) during the year:

- 134 news articles about personal assistance were published.
- *Assistanskoll's* journalist Erik Tillander visited Almedalen in June / July and reported from there.
- Municipal personal assistance providers, like Grums, Uppsala and Täby, can now take part in the comparison service.
- The guide [Att rekrytera personliga assistenter](#) (how to recruit personal assistants) was created which gives personal assistance users help in finding and choosing the right assistant.
- The guide [Anordna din egen assistans](#) (how to organize your own assistance) was created which describes how to start your own personal assistance company, how to seek permissions from authorities etc.
- At the section [Platsannonser](#) (employment ads) you can reach and search the [Arbetsförmedlingen](#) ads on personal assistants and search amongst them and others that assistance providers, municipalities and others publish on the site.

Cooperation with the Non-Profit Membership Association Med lagen som verktyg (MLSV) / "With the law as a tool"

On ILI's initiative, the [non-profit membership association MLSV](#) was established, together with representatives from STIL, DHR, LikaUnika and RTP after being stated that the project [The Law as a Tool](#) financed by the Swedish Inheritance Fund could not include processing cases in court. The membership association assist its members in denouncing cases of discrimination – if necessary in court. The association informs and gives advice concerning disability discrimination, collects means for a "Process fund" and cooperates with a judicial network consisted by human rights lawyers who sometimes can undertake cases *pro bono*.

Especially when it comes to the informative and educational activities there is a close cooperation between the [Association MLSV](#) and the project [The Law as a Tool](#). For example the association and the project now has a joint webpage where it is still clear that it combines the activities of two separate legal entities with different, and complementing, roles. In the membership association's [bylaws](#) the cooperation with ILI is stated and during 2016 ILI contributed with some administrative support. Adolf Ratzka served as the membership association's Board director during the year.

The on-line library and PA-network

[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 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.

Arranging of conferences/ seminars/ educational trainings and participation in events arranged by other actors

During the year, a number of conferences, seminars and training activities were organized and ILI staff participated in other organizations/actors events, including:

- The 19th of April in Genève, the UN Comité on the rights of persons with disabilities invited Adolf Ratzka as a speaker at the *Day of General Discussion* on CRPD Article 19. See a summary: <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=19845&LangID=E>
- The 19th of April in Genève, Adolf Ratzka was invited as a speaker at the 10th Anniversary of the UN Convention on the rights of persons with disabilities (UNCRPD).
- The 11th of May, course lecture in Occupational Therapy at Karolinska Institutets, 3rd semester.
- The 19th of May, the project The law as a tool co-arranged a conference on "The Disability Convention and the law as a tool", together with the HSO project "*Från snack till verkstad*". See [documentation from the conference](#).
- The 20th - 23rd of June, [Fundamental Rights Forum](#) in Vienna.
- The 17th - 19th of November, at the Human Rights Days in Malmö, the project The law as a tool co-arranged a seminar "[The Disability Rights Movement mobilizes itself, it is time to get it right!](#)" together with the HSO project "*Från snack till verkstad*".
- The 24th - 25th of November the project the Law as a Tool arranged a conference and two seminars on [Realizing the promise of CRPD and disability discrimination law: strategic litigation and human rights enforcement](#). See documentation in forms of films and texts: <https://lagensomverktyg.se/tag/dokumentation/>.
- The 14th of December, course lecture in Occupational Therapy at Karolinska Institutets, 5th semester.

Publications, interviews, consultation responses and appearances in various media

ILI's staff published during the year, news articles, text, picture and video material in different media.

- On [Assistanskoll's website](#) 134 news articles about personal assistance were published.
- on [The Law as a Tool's website](#) 15 news articles about disability discrimination were published, as well as information folders and documentation from seminars etc.
- May, interview with Julius Mvenyi Ntobuah on the Swedish Public Radio about disabled asylum seekers.
- June, [Parallell Report: Joint NGO submission review of Sweden](#) to the UN Committee on Economic, Social and Cultural Rights, to give input til the Committee's review of Sweden's commitment under the UNCESCR. The report was elaborated together with the Swedish Foundation for Human Rights and 14 other organizations.
- June, Adolf Ratzka and his legal representative Carin Apelmo from the Bureau for Equal Rights visited the Royal Palace of Stockholm examining the accessibility of the facilities open for the public, if they are really open for each and everyone. lokaler som är öppna för allmänheten verkligen är öppna för alla. Media reportation was published in the [Swedish Public Television](#), [Swedish Public Radio](#) and the newspaper [Dagens Nyheter](#), as well as an [article](#) and a [follow-up article](#) that the project With the Law as a Tool published on the topic.
- Autumn, Adolf Ratzka was interviewed by the magazine [Assistance](#).
- November, Uchina-Inclusive Society, Okinawa, Japan, asked Adolf Ratzka to write an article on inclusive social politics for a publication in the organization's report on this topic.
- November, on its 25th Anniversary of the Personal Assistance Cooperative ULOBA, Norway, Adolf Ratzka was asked to write an article about ULOBA and the development of personal assistance http://www.uloba.no/politikk/Documents/Selvsagt_11_UU.pdf.

Study visits at ILI

During the year ILI received the following visits:

- 9th of May, prof. Yueh-Ching Chou, Ph.D, from the Institute of Health & Welfare Policy, National Yang-Ming University, Taipei, Taiwan. The study visit was about de-institutionalization.
- 30th of June, Mostafa Attia, PhD at the Faculty of Education, Social Sciences and Law, University of Leeds, UK.
- 1st of July, a delegation of 12 juli, delegation på 12 representatived from the Korea Spinal Cord Injury Association with close connection to the Corean Independent Living Movement.
- 12th of September, Jahidul Islam, Dacca, Bangladesh, the Swedish Institute scholar (Young Connectors of the Future Leadership Fellowship) visited Adolf Ratzka.
- 20th of September, Dr Andrew Martel, Faculty of Architecture, Building and Planning, the University of Melbourne, Victoria, Australia visited Adolf Ratzka on the occasion of its upcoming National Disability Insurance and in particular concerning housing and accessible housing adaptation for disabled persons.
- 20th of October, five researchers from the Daejeon Welfare & Hyo Foundation, Korea (a public research foundation in the county of Daejeon). The visit was about policy, implementation and cost comparisons for de-institutionalization.

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:

- 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"](#).

ILI staff

During 2016 the ILI staff consisted of the following individuals, all of whom have been working part time and some only during short periods:

Adolf Ratzka, director.

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 co-worker for *the Law as a Tool*, from May 2016.

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

Johanna Andersson, project leader for *PA-tips* from October 2016, and in before project co-worker.

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

Linda Robertsson, office manager including administration and economy.

Louise Vidlund, project co-worker for *PA-tips*, October – December 2016.

Ola Linder, lawyer and project co-worker for *the Law as a Tool* from October 2016.

Paul Lappalainen, lawyer and project leader for *the Law as a Tool* from March 2016.

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

The following persons have worked on consultancy basis or as interns:

Cecilia Andersson, project leader for *PA-tips* until September 2016 on consultancy basis.

Elena Quiñonez and **Sebastian Ferrer** provided accounting services on consultancy basis.

Julius Mvenyi Ntobuah, intern for the project Disabled Refugees Welcome.

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](#).
- [Petrus & Augusta Hedlunds stiftelse](#) funded the project [PA-tips](#).

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 has been its director since 1993.

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

Judith E. Heumann, Washington DC, USA, was elected as Board member on December 16th. [Judy Heumann](#) is one of the premier internationally known Independent Living activists 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 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](#)); promoter and Director, together with [Ed Roberts](#), for the [World Institute on Disability](#); Assistant Secretary for the Office of Special Education and Rehabilitation Services, [US Department of Education](#) 1993–2001; [World Bank Group](#) first Adviser 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](#).

Susanne Berg, Stockholm, quality developer at [STIL](#) with a focus on self-determination and politics, former member of the [STIL](#) board, project manager for [Fashion Freaks](#) with several ILI projects, freelancer with focus on text, lecturing and analysis. Susanne ended her board assignment in December 16th 2016.

Bengt Elmén, Stockholm, writer, commentator and lecturer, board member in [STIL](#), [STIL](#)'s director 1987-1991. Bengt was Susanne Berg's substitute until December 16th 2016.

The STIL Board at its Board meeting in January 2017 nominated a board member and substitute to the ILI Board, that will decide on their election at its next up-coming Board meeting.

During the year the Board held two ordinary Board, on March 3rd and on December 16th. In addition, the Board has been in regular contact via email and telephone.

Stockholm, 2017-

Adolf Ratzka

Jamie Bolling

Kalle Könkkölä

Kapka Panayotova