

## ANNUAL REPORT 2015

The Independent Living Institute (ILI) promotes opportunities for people with disabilities for more personal and political power, self-determination, full participation and equality through information, education, advocacy and projects.

### Projects

#### ***Personal Assistance Tips***

The three-year project, with financial support from the [Inheritance Fund](#) (Arvsfonden), started in January 2013 and ended in December 2015, yet its activities will continue and develop further.

The project is to collect, document (by text, photos, video or drawings) and spread the tips, tricks and examples that assistance users and their assistants have developed for many assistance situations. 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 website is [patips.se](http://patips.se) and [www.facebook.com/pages/PA-tips/521198964597578](https://www.facebook.com/pages/PA-tips/521198964597578) to which an increasing number of organizations and assistance providers refer their members/customers.

The project was run in collaboration with the co-applicants [STIL](#), [Neuroförbundet](#) (formerly NHR) and [KFO](#), the largest employers' association in the industry. The project has also been followed by a reference group consisting of representatives from [IfA](#), [Hjälpmedelsinstitutet](#), [Spinalistips](#), [Assistansanordnarna](#), the employer organizations [Vårdföretagarna](#) Bransch Personlig Assistans och [KFS](#).

#### ***Fashion Freaks - Remade, Recycled, Revisited***

[Fashion Freaks – Remade, Recycled, Revisited](#) is about fashion, clothing and vanity from a seated perspective. Co-applicant to the [Inheritance Fund](#) is [STIL](#). *Fashion Freaks*' basic idea is that people who use wheelchairs are just as vain as any other. We are all unique individuals with the right to our own taste and style. And yet, it is almost impossible to find stylish clothes sewn for "sitting" forms. *Fashion Freaks* is a wardrobe full of adapted basic patterns, sewing and knitting instructions, descriptions about customizing ready-made

clothing and much more - all to suit wheelchair users. In 2015, knitting patterns were prioritized as well as solutions about how combinations of garments (where knitted parts are included) can be used instead of jackets to keep you warm and how knitted accessories and parts can be used for harnesses, braces or other wheelchair accessories. The project's website is available in English and Swedish language, [en.fashionfreaks.se](http://en.fashionfreaks.se) and [fashionfreaks.se](http://fashionfreaks.se). The website had over 232,000 page views during the year, which is a large increase from 2013. 20% of the visitors were from Sweden, 23% from the US and 57% from the rest of the world.

### ***With the law as a tool***

In October 2015 our project application was finally approved by the [Inheritance Fund](#) after three years of revisions in consultation with the Fund's administrators. See the [final project description](#). Co-applicants are [Handikappförbunden HSO](#), [Apply Human Rights](#), [DHR](#), [STIL](#), and [RTP](#). The project will be followed by a reference group consisting of representatives from MFD, DO, Handikappförbunden and human rights organizations and legal experts on disability discrimination.

The project was preceded by a pilot study, also with financial support from the [Inheritance Fund](#), which concluded that the Swedish disability movement was ill prepared to tackle the discrimination that people with disabilities face. The three-year project aims at improving the understanding of Swedish and international anti-discrimination legislation and legal praxis on the part of disability organizations, the legal community and the public, and at promoting the use of law and legal case work as tools in combatting structural discrimination.

Project activities will be run in cooperation with the [membership organization "With the law as a tool"](#) (Med lagen som verktyg) which was founded during the year and whose activities complement the project's activities. See also "Initiative to the membership organization (With the law as a tool)" below.

The project will also collaborate with "Rights Network Against Discrimination" which was recently started up by among others Apply Human Rights and ILI. The network consists of lawyers, law firms and organizations with legal expertise that are willing to represent various vulnerable groups and individuals so that more discrimination cases can be taken more effectively to court.

### ***Reporting Service***

The [Reporting Service](#) 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 3,300 for discrimination cases have been reported this way. The *Reporting Service* which has not had its own funding will be an important part of project *With the law as a tool* (see above) after updating and adapting to the needs of the project from 2016 and onwards.

## Other ongoing activities

### ***Assistanskoll***

After [Assistanskoll's](#) project period and funding by the [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 2015, 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 499,000 page views during the year (425 000 in 2014 - an increase of 17%). This exposure makes [Assistanskoll's](#) website and newsletter an interesting platform for banner advertisements which cover almost all [Assistanskoll](#) 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.

The site's most popular pages offer a comparison of existing trade union agreements for personal assistance, as well as guides such as "[Working as an assistant](#)", "[What salaries earn personal assistants?](#)" and "[Prepare for your assistance assessment](#)".

[Assistanskoll](#) 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:**

- 104 news articles about personal assistance were published.
- [Assistanskoll](#) journalist Erik Tillander visited Almedalen in June / July and reported from there.
- Municipal personal assistance providers, like Grums and Täby, can now take part in the comparison service.
- The guide "[What have personal assistants in salary?](#)" compiles figures from Statistics Sweden comparing salaries in private companies and municipalities, as well as differences by gender, age and geographical area. The page [OB-ersättning för personliga assistenter](#) shows the unsocial hours compensation for a specific time and date according to trade union agreements.

## **Initiative for the non-profit membership organization "With the law as a tool"**

[The membership organization "With the law as a tool"](#) was founded on the initiative of ILI together with representatives from [STIL](#), [DHR](#), [LikaUnika](#), [SRF](#) and [RTP](#) after it had become clear that the Inheritance Fund-funded project with the same name would not be able to take cases to court. The membership organization had administrative help from ILI during the start-up phase.

The founding meeting of 31 March 2015 adopted [Bylaws](#) where close cooperation with ILI is a stated aim and elected Adolf Ratzka as chairperson for the first year.

### ***Online full-text library***

[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. We often receive appreciative comments from readers in different countries.

## **Participation in other organizations' events**

### **ILI's staff participated in**

- December 3, Halmstad, with Adolf Ratzka as keynote speaker at [event on the International Day of Persons with Disabilities](#) organized by the University of Halmstad and Halmstad municipality.
- October 14 - 15, Bratislava, Adolf Ratzka presented [Independent Living frees citizens with disabilities from residential institutions and dependency on family](#) at the [Closing International Conference on De-institutionalization of Social Services in the Slovak Republic](#), organized by the Slovak Republic Ministry of Employment, Social Affairs and Family
- September 26, ILI was invited to deliberations with Swedish Minister of Social Affairs Åsa Regnér
- June 18 - 19, Lisbon, Adolf Ratzka presented plenary presentation "[Accessible Cities Consist of Barrier-Free Housing](#)" at the EURO CITIES Conference "[Cities for Accessibility, Jobs and Inclusion](#)". At its meeting on June 18, [Centro de Vida Independente elected him to their first honorary member](#).
- 14 April, Berlin, Adolf Ratzka presented via Skype "[Die Voraussetzungen zur De-institutionalisierung von Menschen mit Behinderungen](#)" at the conference [Wohnen für alle - Teilhabe von Menschen mit Behinderungen](#) organized by Klaus Mindrup, member of the German Federal Parliament
- May 20, presentation by Adolf Ratzka at the [Parliamentary Breakfast seminar on Personal Assistance](#), its Costs and the Costs of Alternatives

- 13 May, Stockholm, Adolf Ratzka lectured on cooperative solutions for residents of all ages and needs at the international seminar on Co-housing, organized by Prof. Dick Urban Vestbro, KTH
- May 11, [lecture by Adolf Ratzka at the German embassy in Stockholm](#) on Swedish disability policy for the delegation of the German Federal Parliament Social Committee
- May 8 lecture at Karolinska Institutet occupational training for 5th semester
- March 25 - 26, Cardiff, Adolf Ratzka was [keynote speaker](#) at a conference in Wales, the launch of a [state project on direct payments](#) for personal assistance in cooperative forms; led a workshop on this in Cardiff, was interviewed in the [media](#) and invited to deliberations with the Welsh Social Affairs Minister Prof Mark Drakeford. The conference was based on a [study of cooperative solutions in personal assistance](#) to which AR had contributed.
- March 13, Athens, Adolf Ratzka lectured at the workshop "Policies on Disability and Disability in Politics" via Skype about ["What role can Independent Living play in a country in economic crisis?"](#). The [event](#) was organized by MEP Kouneva Kosta Tina from the government party Syriza and the Foundation Nikos Polulantzas.

## **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](#) 104 news articles about personal assistance were published.
- December 5, Austrian TV ORF / Welt Journal in its series "Leben ohne Barrieren" ("Life without barriers") [interviewed Adolf Ratzka](#) on personal assistance.
- October 11 to 16, ILI signs *list of issues* for future alternative report to the ESC Committee. Presented at ESC Committee's pre-session.
- October 15 Adolf Ratzka's presentation ["Independent Living frees citizens with disabilities from residential institutions and dependency on family"](#) was published in [Proceedings of International Conference Closing International Conference on De-institutionalization of Social Services in the Slovak Republic](#) convened by Slovak Republik Ministry of Employment, Social Affairs and Family
- June 2, Aiai magazine, ILI's [Adolf Ratzka interviewed](#) about the initiative of the membership organization "With the law as a tool".
- June 2, Aiai magazine page 28-30, ["Tipstjänsten där du kan ge och ta"](#) ("The tips service where you can give and take") reports about Nina Muhonen.
- 15 May, [Neuroförbundet](#) internet radio reports about the state of the assistance reform, [interviews among others Adolf Ratzka](#).

- May 4, [Zero Project interviews Adolf Ratzka](#) on personal assistance and its importance in peoples' lives.
- Funkaportalen.se features article entitled "[Assistanstips - en sajt med tips om assistans](#)"
- Magazine "Assistans" no. 3 2015 publishes "[Går det att bli mer lyhörd?](#)" ("Can you become a better listener?") by Erik Tillander.
- April 13, [Co-operative News](#) reports about Adolf Ratzka's presentation at the conference about direct payments for personal assistance in co-operative forms in Cardiff in connection with the release of the report [Citizen Directed Care Co-operative](#) to which Adolf Ratzka contributed.
- Magazine "Assistans" no. 3 2015 pages 26-27 publishes article "[Låt ingen annan bestämma hur du ska leva](#)" ("Don't allow anybody to run your life!") by Erik Tillander and Johanna Andersson.
- March 20, article in [Fulldelaktighet.nu](#), by Adolf Ratzka about the new membership organization "[With the law as a tool](#)".
- March 20, [HejaOlika.se](#) reports about the new membership organization "[With the law as a tool](#)".
- March 2, SVT News [interviews, among others, Adolf Ratzka](#) about the National Social Security Fund's growing tendency to reject applications for personal assistance.
- Feb. 18, *Assistanstips* project leader Nina Muhonen participated in TV Talkshow Go'kväll.
- February 11, the periodical [Funktionshinderpolitik](#) interviews Adolf Ratzka about his proposal for a new benefit from the National Social Security Fund in the form of direct payments for assistive technology.
- February 11, periodical "Dagens samhälle" publishes Adolf Ratzka's article "[Låt hjälpmedelsanvändare själva avgöra sitt eget bästa](#)". ("Let users of assistive technology decide in their own best interest!")
- Magazine "Assistans" no. 2 2015 pages 26-27, article "[Rätt assistent för rätt uppgift](#)" ("Right assistant for right task") by Erik Tillander.
- Magazine "Assistans" no. 1 2015 page 19, publishes article "[Förnuft och känsla i anställningsprocessen](#)" ("Reason and feeling in the recruitment process") by Erik Tillander.

## Study visits to ILI

ILI received the following visits:

- September 9, Matilda Fuchs, chairperson of [Gré à Gré](#) together with Eve Gardien, researcher at the University of Rennes, France

- September 8, a study visit from Australia's equivalent of National Social Security Fund for persons with disabilities
- August 17 to 21, Kazuo Nishikawa, Center for Independent Living, Osaka, Japan
- May 27, study visit from Nepal

## **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 [membership organization "With the law as a tool"](#)

## **ILI staff**

ILI's staff consisted of the following individuals, all of whom have been working part time:

- **Johanna Andersson**, project officer for [Assistance Tips](#) as of June
- **Susanne Berg**, project coordinator for [Fashion Freaks](#)
- **Philip Day**, webmaster, database programmer and project staff for [Assistanskoll](#), also working with [Reporting Service](#) and [Assistance Tips](#)

- **Algren Morgan**, project officer for [Assistanskoll](#), responsible for contacts with the assistance providers and municipal LSS administrators.
- **Nina Muhonen**, project coordinator for [Assistance Tips](#) until September.
- **Adolf Ratzka**, Director
- **Linda Robertson**, Head of Office with responsibility for administration, finance and project coordination.
- **Susanne Sundberg**, project staff for [Assistance Tips](#) until May.
- **Erik Tillander**, project officer for [Assistance Tips](#) and [Assistanskoll](#) substituting as freelance journalist during Kenneth Westberg's parental leave.
- **Kenneth Westberg**, journalist and project coordinator for [Assistanskoll](#) with responsibility for content and direction incl. newsletters, statistics and analysis, news and in-depth articles about personal assistance
- **Meagan Whellans**, project staff for [Fashion Freaks](#)
- **Cecilia Andersson**, project coordinator for [Assistance Tips](#), as of October as consultant
- **Sebastian Ferrer** and **Elena Quinonez**, economic services on a consulting basis

## Funding

With thanks to:

- [STIL](#)/ILU, founders of Independent Living in Sweden, contributed to ILI's operations through financial support
- Arvsfonden ([Inheritance Fund](#)) funded projects [Assistance Tips](#) and [Fashion Freaks](#)
- The magazine *Assistans* contributed financially to project [Assistance Tips](#)

In addition, ILI's activities were funded by banner advertisements on [Assistanskoll](#)

## Board composition and board meetings

**Kalle Könkkölä**, Helsinki, 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 etc

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

**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](#).



**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 ILLI projects, freelancer with focus on text, lecturing and analysis. Susanne was elected as a new board member in May.

**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 .

**Bengt Elmén**, Stockholm, writer, commentator and lecturer, board member in [STIL](#), [STIL](#)'s director 1987-1991. Bengt was elected as a deputy for Susanne Berg on 31 August.

During the year, the Board held two ordinary meetings, on 22 May and 31 August. In addition, the Board has been in regular contact via email and telephone.

**Stockholm, March 3, 2016**

Kalle Könkkölä    Kapka Panayotova    Jamie Bolling    Susanne Berg    Adolf Ratzka,  
chair.