

Independent Living Institute

Annual Report 2014

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

Project activities

Assistanstips (Personal Assistance Tips)

The three-year project Assistanstips began in January 2013 with financial support from the Swedish Inheritance Fund (Allmänna Arvsfonden). Co-applicants were STIL (Stiftarna av Independent Living i Sverige), Neurologiskt Handikappades Riksförbund (NHR) and KFO, the largest employers' association in this field. The project has an advisory reference group consisting of representatives of lfA (the association of personal assistance users), the Swedish Institute of Assistive Technology, Spinalistips, Assistansanordnarna, and the employer associations Vårdföretagarna and KFS. The project shall collect, document (with text, image, video or drawings) and disseminate tips, tricks and examples of assistance solutions developed by personal assistance users and their assistants. According to the Independent Living philosophy, people with disabilities are the best experts on their needs. Therefore we can learn from and help each other improve our assistance services' quality and increase our self-determination in daily life. This requires, among other things, knowledge of practical and organizational solutions, e.g. about how assistants can work with a certain assistance task. The idea is not to show 'the best' solution for all assistance users, as we are not a homogeneous group but individuals with unique backgrounds, needs and preferences. Rather, it is to suggest various solutions that assistance users can test and receive inspiration from for developing their own methods. The project also encourages assistance users, their relatives, assistants and other professionals working with personal assistance to improve assistants' work environment. The project website is www.patips.se and can also be found on www.facebook.com/pages/PA-tips/521198964597578. More and more organizations, including private personal assistance providers, can now link to the project website as well as inform their members/clients through their respective information channels.

Fashion Freaks – Remade, Recycled, Revisited

Fashion Freaks – Remade, Recycled, Revisited is a project about fashion, style and vanity from a sitting viewpoint. The co-applicant is STIL. Fashion Freaks basic tenet is that wheelchair users are just as vain as the rest. We are all unique individuals with the right to our own taste and style. Yet it is near impossible to find smart clothes suitable for sitting. Fashion Freaks is a wardrobe full of adapted basic patterns, sewing tutorials, instructions on how to modify ready-made garments, and much else - all to suit wheelchair users. In 2014, the focus has mainly been on solutions and information combining the information that already exists on the website. There is information of a more general nature such as, for example, what you should consider when you sew or alter clothes, and how to get the best result if you want to knit a garment or combine several garments/accessories. The focus is on showing examples of adjustments made, garment combinations and different kinds of garments/accessories that exist which can be both fit to use and 'funky'. The English and Swedish website sections had more than 232,000 page views combined during the year. This is a considerable increase from 2013. 20% of the visitors were from Sweden, 23% from the US and 57% from the rest of the world.

PA-nätverket (Personal Assistance Network)

PA Network informs non-Swedish visitors about personal assistance in Sweden through articles in English on ILI's homepage. With financial support from ULOBA we summarize articles found in Swedish on www.assistanskoll.se which are concerned with most aspects of personal assistance legislation and its implementation. The summaries are to give a comprehensive overview of the Swedish personal assistance situation, its key players, and their arguments and positions on many issues. Another aspect of the PA Network concerns translations of some of our Swedish articles on the situation of assistance users in other countries. Most translations are in English but some articles are also available in Spanish, German, French and Dutch.

Other ongoing activities

Assistanskoll

In June 2010, after the end of financial support from the Swedish Inheritance Fund (Allmänna Arvsfonden), Assistanskoll (roughly translated to 'control over your assistance') has continued to increase its content and exposure. *Assistanskoll* offers information, facts and figures, analysis and advice to personal assistance users, their families and assistants in choosing a service provider and updates the public about the fast changes in personal assistance legislation, legal praxis and market development.

Assistanskoll is also used by municipal case workers who are to inform assistance users and their families about their choices in this market. At the end of 2014, 234 private personal assistance providers participated in Assistanskoll's comparison service. These providers together serve a total of 10,414 customers or members which corresponds to 85 per cent of the Swedish private personal assistance market. *Assistanskoll's* homepage had more than 192,000 page views during the year (150,000 in 2013). The exposure has made Assistanskoll's homepage and newsletter a lucrative space for advertisers, enabling the service to break-even financially.

Assistanskoll's newsletter, written and published monthly by Kenneth Westberg, has gained a leading position in monitoring the development of personal assistance in Sweden. Our articles and other information are often referred to. The newsletter reaches 6,500 email addresses of which many are assistance providers and local government case workers. The remaining subscribers are personal assistance users, their families and assistants, disability organizations and their periodicals, trade unions, civil servants and politicians at all levels.

Popular content includes pages with contracts between the trade unions and their employer association counterparts as well as our guide Working as a personal assistant. *Assistanskoll* also has a comprehensive page of statistics such as the two-year-reassessment of Försäkringskassan (The Swedish Social Insurance Agency), assistance costs and which municipalities procured their assistance units.

Examples of *Assistanskoll's* activities during the year:

- 98 news articles about personal assistance published on its homepage.
- *Assistanskoll's* journalist Erik Tillander reported from Almedalen Week.
- Questions to the personal assistance providers that participate in the comparison service has been upgraded/improved and new questions have been added in order to adjust the questions to new laws and government decisions.
- Municipal personal assistance providers are now able to participate in *Assistanskoll's* comparison service. As of December, the municipality of Grums was the first to register.
- The guide Prepare yourself for your personal assistance assessment has been improved. This guide assists assistance users in how to apply for direct payments for personal assistance for the first time, or to prepare for an upcoming review of their assistance needs. One of its features is the Assistance Needs Calculator facilitating self-assessment. The guide has become a popular tool among assistance users and providers.

Med lagen som verktyg (Using the law as a tool)

During 2014 the 3-year application “*Using the law as a tool*” was finalized and presented to The Swedish Inheritance Fund. Co-applicants are Handikappförbunden HSO, Apply Human Rights, DHR, STIL, och Personskadeförbundet RTP. Previously a pre-study was conducted, financed by The Swedish Inheritance Fund, which concluded that the Swedish disability movement should have better legal skills so as to respond to the discrimination faced by disabled people. This 3-year project shall increase the disability movement’s access to legal expertise when it comes to education, and the defense and development of human rights for persons with disabilities. The aim is to contribute so that the human rights of disabled people are guaranteed to a larger extent using the law and case law practice as a tool to fight negative special treatment and structural discrimination.

A seminar was held on 23rd May entitled “Disability discrimination in Europe – opportunities and difficulties to demand their rights in court” in which a number of Swedish and foreign experts (including the ILI board) highlighted different discrimination cases with a subsequent conversation about its effects, and future strategies to strengthen the protection of this group’s human rights.

In parallel with the application process ILI, together with the NGO Apply Human Rights, and the equality advice bureau Diskrimineringsbyrån Uppsala, formed a network called *Rättsnätverket* (literally “The Rights Network”). *Rättsnätverket* consists of lawyers, law firms and organizations with legal skills who are dedicated to defending and promoting the rights of groups at risk of discrimination. This way cases of discrimination can be brought to court in a more effective manner. The purpose is to build up, gather and spread legal expertise about discrimination on all grounds including disability, to establish a litigation unit, conduct courses and training seminars and solicit legal *pro bono* work from network members. A questionnaire has been circulated among the legal community and, as a result, within a fortnight two dozen lawyers indicated their interest in human rights training and in contributing *pro bono* work.

In addition to *Rättsnätverket*, formal cooperation with other disability organizations has been established to compliment and reinforce each other’s activities in combating discrimination on the grounds of disability. The project has received letters of recommendation from two dozen national and international legal experts on discrimination against disabled people.

Anmälningstjänsten (The Equality Ombudsman Reporting Service)

The online Discrimination Reporting Service (in Swedish) assists individuals and organizations in reporting discrimination to the office of the Equality Ombudsman and the respective local government building permit board. The service offers a number of pre-formulated statements on its homepage that can be selected with a mouse click. The reported cases are documented in a Google-searchable public database. The service contains over 3,300 reports of discrimination. The project has not had its own funding and we are still looking for a more sustainable financial solution.

Online full-text library

ILI’s online full-text library offers to authors: publishing, exposure and safe archiving of their work, such as articles in scientific journals, reports, manuals and lectures on Independent Living and related themes. There are currently over 600 (mostly) English documents in the searchable library including over 200 in Swedish and approximately 100 in other languages such as Spanish, French and German. The library contains, for example, a number of bibliographies such as that put forward by British scientist M. Miles on the treatment of people with disabilities in Asian cultures. We often receive appreciative comments from readers in different countries.

Participation in other organizations' events

The ILI Director and staff took part in the following events during 2014:

- 18th February – lecture at a seminar on housing and service alternatives, organized by Kollektivhus.nu for the EU-project CoElderly, Stockholm.
- 5th April – participation at the council meeting and discussion forum of IfA, including a presentation of Assistanstips.
- 8th May – course lecture at the 5th year curriculum in Occupational Therapy, Karolinska Institutet, Stockholm.
- 14th June – presentation “What is Independent Living?” at ULOBA’s national seminar on Independent Living, Oslo.
- 26th September – participation of Assistanstips in Möjlighetsdagen. This was a series of seminars on opportunities, solutions and rights of persons with disabilities, arranged by Rehab Station, Personskadeförbundet RTP, BOSSE råd, stöd och kunskapscenter, DHR and Neuroförbundet, Stockholm.
- 15th-16th October – participation of Assistanstips in the exhibition “Fokus Hjälpmedel” (Focus on assistive devices), Västerås.

During the year the ILI Director was invited to lecture at the following events, which he unfortunately had to decline.

- 23rd August – invited panel commentator at GIL's event on the occasion of 20 years with the law LASS/LSS, Gothenburg.
- 1st-2nd October – invited to give a presentation in connection with a meeting organized by Nätverket för socialvetenskaplig äldreforskning (Network for Social Science Aging Research), Sigtuna.
- 20th October – invited lecturer of the course ‘Equality Law’ from the International Law Division of the University of Stockholm.
- 28th November – invited keynote speaker at “Konventionen in den Hague Fokus Society”, Netherlands.
- 2nd December – invited lecturer at the Congress “Inklusion 2050”, Berlin.
- 3rd December – invited lecturer at the International conference about self-determination of persons with disabilities, organized by the government of San Marino.
- 17th December – invited course lecturer at the 3rd year curriculum in Occupational Therapy, Karolinska Institutet, Stockholm.

Publications, interviews and comments on official reports and appearances in different media

During the year the ILI staff published articles, text and image material in different media.

- Assistanskoll published 98 articles about personal assistance during the year.
- An interview on 18th February in Svensk Handikapptidskrift “Tillgänglighet och inkludering är eftersatt i Sverige”.
- In a news report about 20 years with direct payments for personal assistance, former ministers Bengt Westerberg, Bengt Lindqvist and the Independent Living Movement’s Adolf Ratzka were interviewed for Tidningen Assistans nr. 2.
- ILI was one of the consultation bodies to the official report “Förändrad assistansersättning – en översyn av ersättningssystemet (SOU 2014:9) and the response welcomed the investigation’s proposal on agreements between the assistance user and the assistance provider, and rejected the investigation’s proposals leading to lower levels of assistance payments.

- For Assistanstips several articles/interviews were published during the year. In Tidningen Assistans no. 2 "Assistans och PA-tips inleder samarbete", no. 3 "Assistent och vän eller bara professionell. Många PA-tips handlar om arbetsledarrollen", no. 4 "Många tips om att leva som man vill", no. 5 "Var tydlig - och undvik konflikter med assistenten". In Svensk Handikapptidskrift in June "De tipsar varandra om personlig assistans".
- Adolf Ratzka wrote the foreword to a photobook portraying persons with disabilities and their daily life. The book was published by the organization NPA-Iceland that promotes direct payments for personal assistance in Iceland.
- In Socialvetenskaplig Tidskrift no.3-4, an article by Adolf Ratzka was published "Nej till åldersbegränsningen av mänskliga rättigheter! Ja till personlig assistans efter behov inte ålder!".
- Adolf Ratzka was interviewed by Christa Hofmann in the television program "Leben ohne Barrieren". The reportage reflected the situation of disabled people in four different countries, including Sweden and the assistance reform. The TV program was broadcast on Austrian television on 2nd December tv.orf.at/weltjournal.

Study visits at ILI

ILI received the following study visits during the year:

- 27th January – visit by Pro Dr Theresia Degener, Professor of Law and Disability Studies, legal expert German government and member of the Government Delegation to the United Nations Ad Hoc Committee on the Convention on the Rights of Persons with Disabilities. The visit included an exchange of experience with Annika Åkerberg, Luris Humani and Paul Lappalainen, Equality Ombudsman (DO).
- 13th May – study visit by 8 delegates of the Japanese Independent Living Centers, Okinwa and Hyrena prefecture.
- 19th May – study visit by the Swiss organization Pro Infirmis Landesverband.
- 23rd October – study visit and interview for Assistanskoll, Alix Goodwin, Australia.

Cooperation with the Swedish and international disability movement 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 was co-applicant for a joint project "Disabled voices of Ukraine", together with Human Rights Foundation-Ukraine and Threshold-Finland. The project, however, could not be implemented.

During the year ILI staff members have served as:

- Advisory Board member of the project AGERA – Utan att diskriminera.
- Overseas Editor and peer reviewer for the scientific journal "Disability and Society", UK.

- Distinguished Fellow och “peer reviewer” för tidskriften ”The Review of Disabilities Studies”, Center on Disability Studies, University of Hawaii.
- Member of the “Scientific Advisory Board”, Hungarian Quarterly of Disability Studies, Budapest, Hungary.
- Member International Advisory Council, Ecoplan.
- Board Member Stiftelsen till Rolf Bergfors minne.
- Board Member Access Sweden.
- Member of Scientific Advisory Board World Future Council for International Conference on Good Policies for Persons with Disabilities, Vienna.

ILI staff

The ILI staff consisted of the following part-time workers:

- **Susanne Berg**, project leader of Fashion Freaks.
- **Philip Day**, webmaster, programmer and project worker for Assistanskoll, Discrimination Reporting Service and Assistanstips.
- **Algren Morgan**, project worker for Assistanskoll responsible for address update and contacts with personal assistance providers and municipal administrators.
- **Nina Muhonen**, project leader of Assistanstips.
- **Adolf Ratzka**, director and project leader of PA-network.
- **Linda Robertsson**, office manager incl. administration, financial administration and project coordination.
- **Susanne Sundberg**, project worker for Assistanstips.
- **Erik Tillander**, project worker for Assistanstips and freelance journalist for Assistanskoll, substitute during Kenneth Westberg’s parental leave.
- **Kenneth Westberg**, journalist, project leader of Assistanskoll, responsible for editorial contents and coordination, incl. newsletters, articles, guides, statistics and analyses on personal assistance.
- **Meagan Whellans**, project worker for Fashion Freaks.
- **Sebastian Ferrer** and **Elena Quiñonez**, provided accounting and financial advisory services on consultancy basis.

Funding

We thank:

- STIL/ILU, (Founders of Independent Living in Sweden), for its financial support to ILI’s activities.
- The Swedish Inheritance Fund (Allmänna Arvsfonden) for its financial support to Assistanstips and Fashion Freaks.
- Tidningen Assistans for its financial contribution to Assistanstips.
- ULOBA, the Norwegian personal assistance user cooperative, for its friendship and financial support of PA-network, publishing and translating articles on personal assistance in Europe.

In addition, ILI’s activities have been financed by advertisements on Assistanskoll.se.

Board composition and meetings

Kalle Könkkölä, Helsinki, Finland, Executive Director of Threshold, the first European Independent Living Center which he started in 1973, co-founder of the Finnish Green Party, former Finnish Member of Parliament, former President of Disabled People's International, founder and chair of Foundation Abilis and much more.

Kapka Panayotova, Sofia, Bulgaria, Chair of ENIL, the European Network on Independent Living, founder and Director of Center for Independent Living, Sofia.

Jamie Bolling, Härmösand, Sweden, human rights defender focusing on disability issues, former member of Green Party National Board, former Chair of STIL, researcher and current Executive Director of ENIL.

Susanne Berg, Stockholm, in charge of quality development at the STIL association focusing on self-determination and politics, former board member of STIL, project leader of Fashion Freaks as well as other Independent Living-projects and freelancer focusing on texts, lectures and analysis. Susanne was elected new board member in May.

Adolf Ratzka, Stockholm, Sweden, researcher at KTH 1982–1994, specializing in accessibility and its costs and benefits, imported the Independent Living philosophy to Scandinavia in 1983, started and chaired STIL until 1995, founding chair of ENIL 1989-1992, founding director of Independent Living Institute since 1993.

During the year, the Board held two ordinary board meetings, on 23rd and 24th. Additionally a joint board meeting of both ILI and STIL boards was held on 23rd May aiming at improving the information exchange of the organization's respective activities as well as exploring opportunities of future cooperation and joint projects. In addition to the meetings the Board has had regular contacts by mail and telephone.

Stockholm, 19th May 2015

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