

## New Projects

### [Assistanstips](#) (*Personal Assistance Tips*)

The three-year project [Assistanstips](#), with financial support from the Swedish Inheritance Fund (Allmänna Arvsfonden) began in January 2013. 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 [IfA](#), the association of personal assistance users, the [Swedish Institute of Assistive Technology](#), [Spinalistips](#), [Assistansanordnarna](#), 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, for example, about how assistants can work with a certain assistance task. The idea is not to show "the best" solution for all assistance users - we are not a homogeneous group but individuals with unique background, needs and preferences – but to suggest various solutions that assistance users can test and get 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 can also be found on [Facebook](#)

### *Fashion Freaks – Remade, Recycled, Revisted*

[Fashion Freaks – Remade, Recycled, Revisted](#) is a project about fashion, style and vanity from a sitting viewpoint. *Fashion Freak's* 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 pretty much impossible to find smart clothes fit to sit. Fashion Freaks is a wardrobe full of adapted basic patterns, sewing instructions, instructions on how to modify ready made garments and much else - all to suit wheelchair users. In 2013, the focus was mainly on the "Recycled" part, *i.e.* how off-the-hook garments can be adapted to one's shape. The website's [English](#) and [Swedish](#) versions together had 108 000 unique visitors during the year, of which 25% were from Sweden, 22% from the U.S. and 53% 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 of [ULOBA](#) we summarize articles on most aspects of personal assistance legislation and its implementation found in Swedish on [www.assistanskoll.se](#). The summaries are to give a comprehensive overview of the Swedish personal assistance situation, its key players, their arguments and positions on many issues. Another part of the PA Network consists of 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 on-going activities

### *Assistanskoll*

After the end of financial support by the [Swedish Inheritance Fund](#) (Allmänna Arvsfonden) in June 2010 [Assistanskoll](#) (approximately “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 2013 236 private personal assistance providers participated in [Assistanskoll's](#) comparison service. These providers together serve a total of 9,888 customers or members which corresponds to 86 per cent of the Swedish private personal assistance market. *Assistanskoll's* homepage had more than 106,000 unique visitors during the year (85,000 in 2012). The exposure has made [Assistanskoll's](#) homepage and newsletter an interesting forum also for advertisers enabling the service to break-even financially.

[Assistanskoll's](#) newsletter written and published about 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 6,050 email addresses of which approximately 725 are assistance providers and 1,000 are 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 include the pages with contracts between the trade unions and their employer association counterparts as well as our guide [Working as a personal assistant](#).

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

- 82 news articles about personal assistance published on its homepage.
- Production of the guide [Prepare yourself for your personal assistance assessment](#) which assists assistance users about to apply for direct payments for personal assistance for the first time or those who face 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.
- The list of authorized personal assistance providers issued by the [National Board of Health and Welfare](#) is being integrated in the provider comparisons.
- [Statistics](#) on personal assistance are now grouped on one page, such as the results of the Swedish Social Insurance Agency's bi-annual needs assessments, statistics about personal assistance costs and a list of municipalities where private subcontractors instead of municipal departments provide assistance services.

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

In 2011 and 2012 [The Swedish Inheritance Fund](#) financed our pilot study *Using the law as a tool*. Co-applicants were then [DHR](#), [RTP](#), [STIL](#), [International Commission of Jurists - Swedish Section](#) and the disability organizations umbrella [Federationen Lika Unika](#). The purpose of the study was to assess the feasibility of and the requirements for a three-year project which would build up legal expertise on discrimination on the grounds of disability to defend the rights of disabled people by using existing Swedish and international (EU and UN) law and legal practice.

In 2013 the work on the 3-year project application has progressed and extensive planning and networking has taken place to build a solid foundation for the future project. ILI, together with the NGO [Apply Human Rights](#), and the equality advice bureau [Diskrimineringsbyrån Uppsala](#) formed a network called *Rättsnätverket* (approximately “The Rights Network”). An op-ed [article was published in UNT](#) (the largest newspaper in Uppsala) about this new association. *Rättsnätverket* consists of lawyers, law firms and organizations with legal skills dedicated to defending and promoting the rights of groups in risk of discrimination, so that cases of

discrimination can be brought to court in a more effective manner. The purpose is to build up, gather and spread legal expertise on 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 couple of weeks 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 complement and reinforce each other's activities in combatting 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 by 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 authors publishing, exposure and safe archiving for their work, such as articles in scientific journals, reports, manuals and lectures on Independent Living and related themes. There are currently over 600 mainly English language documents in the searchable library including over 200 in Swedish and approximately 100 in other languages such as Spanish, French and German. Due to our website's good Google Page Rank the library is widely known and receives currently some 200,000 unique visitors a year.

ILI's homepage continued also in 2013 to be the first [search result for "Independent Living"](#) in Google.

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

ILI took part in the following events during 2013:

- April 3 - 4, [LSS from a children's perspective](#), conference in Stockholm.
- May 10, webinar on Planned DPO Cooperatives in Dudley, West Midlands, UK,
- May 14, course lecture at the first year curriculum in Occupational Therapy, Karolinska Institutet, Stockholm.
- September 6, Plenary Presentation "[Back to Our Roots](#)", ENIL's Strasbourg Freedom Drive, on what needs to be done to turn rights stipulated in the UN Convention on the Rights of Persons with Disabilities into reality
- November 9, Münchner Aussen Kongress MAIK in Munich. keynote [Self-determination with respiratory aids](#) (in German).
- December 3, keynote [Independent Living for people with disabilities: from patient to citizen to customer](#). [See video](#). at Conferência Internacional "Vida Independiente – a Nossa vida nas nossas mãos" (Our lives in our hands), International conference in Lisbon.
- December 20, course lecture at the first year curriculum in Occupational Therapy, Karolinska Institutet, Stockholm.

The ILI Director was invited with payed expenses to the Second Zero Project Conference, on February 18 - 19 in Vienna, but was unable to attend.

## Publications

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

- Assistanskoll published 82 articles about personal assistance during the year.
- Opening presentation at MAIK-Münchner Ausserklinischer Intensiv Kongress. "[Selbstbestimmung und Atemhilfen](#)" (in German).
- [Westerberg B.](#) 2013. "[Personal Assistance - a revolution for people with disabilities](#)" Keynote by former Swedish [Minister for Health and Social Affairs, Bengt Westerberg](#) at the international research meeting on social work in Los Angeles in June where he spoke, among other things, about STIL's and Ratzka's role in bringing personal assistance to Sweden.
- [Berg S.](#) 2013. [Report from the feasibility study - With the law as a tool for change](#) (in Swedish).
- "[Back to Our Roots](#)" [Adolf Ratzka Plenary Presentation ENIL Strasbourg Freedom Drive September 6, 2013](#).
- Op-ed article in [UNT 2013-07-05 Fritt fram att diskriminera i Sverige?](#) (in Swedish)., together with the Anti-Discrimination bureaus, ApplyHumanRights and the Swedish section of the International Commission of Jurists. The article served as kick-off for the planned Anti-Discrimination network with litigation mandate.
- Approximately 30 translations of articles on personal assistance in Sweden and Europe, as part of project Personal Assistance Network, have been published at the ILI on-line full-text library.

## Interviews

During the year, ILI's Director was interviewed for the following publications:

- "Le Pape de l'indépendance", [Such](#), French webzine.
- "The Pope of Independence" (English translation of the above mentioned interview) in [Such Webzine No 1 November 2013](#) on how Independent Living and personal assistance was introduced to Europe and Scandinavia.
- "[Personal thinking about personal assistance](#)" interview by [Peter Anderson-Pope](#) (in Swedish) about the introduction and progress of direct payments for personal assistance, in the periodical *Kick of Rekryteringsgruppen*, autumn 2013.
- [Vision](#), the news magazine of the trade union Vision, October
- [KFO's anniversary magazine](#), May.

## Study visits at ILI

ILI received the following study visits during the year:

- January 22, [Ciara Siobhan Brennan](#), Ireland. Ph D student at Reykjavik.
- February 18, delegation of students from the [Hong Kong Institute of Education](#).
- March 5, Mai Kiyohara, researcher from Japan.
- April 17, Adriana Pérez Carreons, [DECLIC](#), Mexico City.
- May 2, [the Committee on Social Affairs of the Baden-Württemberg Parliament](#), Germany.
- May 12, a delegation of social work students, [Catholic University of Applied Science, Münster](#), Germany.

- June 12, students from the [Hong Kong Institute of Education](#).
- June 26, Mathilde Fuchs, chairman of [Asociacion Gre a Gre](#), Rennes, France.
- October 21, 15 representatives from the [japanese association for persons with respiratory aids](#).

### **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, employment. Inquiries may involve projects, literature sources, referral to other organizations, resource persons or may regard individuals looking for support and advice. Currently we spend on average almost 25% of a full-time position on this activity – costs which are hard to recover due to our mainly project based funding structure.

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](#).
- **Malin Nilsson**, worked May-November for [Fashion Freaks](#).
- **Adolf Ratzka**, Director, project leader of [PA-network](#), consultant for [Assistanstips](#) and [Assistanskoll](#).
- **Linda Robertsson**, administrator incl. project coordination and financial administration.
- **Karin Schlyter**, project worker January-June for [Assistanstips](#).
- **Susanne Sundberg**, project worker for [Assistanstips](#).

- **Erik Tillander**, 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.
- [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.
- [The Swedish Inheritance Fund](#) (Allmänna Arvsfonden) for its financial support to [Assistanstips](#) and [Fashion Freaks](#).

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**, Härnösand, 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](#). Jamie was elected new board member in June.

**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.

**Bente Skansgård**, Oslo, passed away November 14, 2013. Bente started [ULOBA](#), the Norwegian counterpart of STIL, chaired [ENIL](#), served in the 1980's as local politician and researcher at [Norwegian Building and Infrastructure Research Institute](#) on housing issues. Bente was not only a board member, she was a co-fighter and close friend.

The Board held two meetings during the year, on June 20 and December 13, in addition to regular contacts by mail and telephone.

Stockholm, May 23, 2014

Kalle Könkkölä

Kapka Panayotova

Jamie Bolling

Adolf Ratzka, chair