

New projects

The application for project Assistanstips was submitted to the Swedish Inheritance Fund (Allmänna Arvsfonden) in April and approved for support in September. Work began in January 2013. Our partners in the application are STIL, Neurologiskt Handikappades Riksförbund (NHR) and KFO, the industry's largest employer association. The project is accompanied by a reference group consisting of representatives for IfA, the Swedish Institute of Assistive Technology, Spinalistips, Assistansanordnarna and the employer associations Vårdföretagarna Bransch Personlig Assistans and KFS. The project compiles, documents (by text, photos, videos or drawings) and disseminates tips, tricks and examples for assistance solutions developed by personal assistance users and their assistants. According to the Independent Living philosophy persons with disabilities are the best experts on their needs. Therefore we have to learn from and help another change our situation. By becoming better bosses for our assistants we improve our assistance service and self-determination in daily life. For that we need, among other things, experience and knowledge of practical and organizational solutions, for example, about how assistants can work in a given assistance situation. The aim is not to show "the best" solution for all assistance users – we are not a homogenous 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 encourages assistance users, their relatives, assistants and other professions working with personal assistance to improve service quality and assistants' work environment.

Project *PA network* informs non-Swedish visitors about personal assistance in Sweden through articles in English. With financial support of ULOBA we summarize articles on most aspects of personal assistance legislation and its implementation which today can be 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 and are published in English on ILI's homepage. The project also translates our Swedish articles on the situation of assistance users in other countries.

Ongoing activities

The pilot study *Using the Law as Tool for Social Change (Med lagen som verktyg)* was started in December 2011 financed by the Swedish Inheritance Fund with Susanne Berg as project coordinator. The study assesses the feasibility of and the requirements for a three-year project which would build up legal expertise on discrimination on the grounds of disability among Swedish disability organizations. The objective is to better utilize existing legislation and legal practice at the Swedish, European, EU and United Nations level for defending the human and civil rights of persons with disabilities. An interim report was submitted to the Inheritance Fund in September, the application for the three-year project is not finished yet.

The Equality Ombudsman Reporting Service (Swedish language) assists individuals and organizations in reporting discrimination to the office of the Equality Ombudsman and the respective local government building permit board by offering multiple pre-formulated statements on its homepage that can be selected by a mouse click. An important tool for discrimination reporting campaigns organized by the annual March for Access (Marschen för tillgänglighet) throughout the country the service documents the extent of discrimination against persons with disabilities in a Google searchable public database. The service contains over 3,000 reports of discrimination. The service has not had its own funding and we are still

looking for a more sustainable financial solution. The service was moved to its own website during the year.

After project Assistanskoll's (approximately “control over your assistance”) financial support by the Swedish Inheritance Fund (Allmänna Arvsfonden) came to an end in June 2010 the service 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* also supports municipal case workers in informing and advising personal assistance users and their families. By the end of 2012 216 private assistance providers had joined Assistanskoll's provider comparison. These providers together report a total of 9,074 customers/members which represents approximately 79% of the Swedish private personal assistance market. Assistanskoll's newsletter published approximately monthly, written 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 almost 5,100 email addresses of which approximately 560 are assistance providers and 975 are local government case workers. Remaining subscribers are personal assistance users, their families and assistants, disability organizations and their periodicals, trade unions, civil servants and politicians at all levels. Assistanskoll's homepage had 85,000 unique visitors (68,000 in 2011). The exposure has made Assistanskoll's homepage and newsletter an interesting forum also for advertizers which cover the lion's share of *Assistanskoll's* running costs.

Examples for *Assistanskoll's* activities during the year are:

- 116 news articles about published on its homepage.
- The list of assistance providers authorized by the National Board of Health and Welfare has been integrated in the comparisons.
- *Assistanskoll* got its own homepage and domain www.assistanskoll.se. Its looks and functionality have been improved by, for example, pull-down menus for navigational ease.
- 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 the costs of direct payments for personal assistance as well as the list of local governments that contract private firms instead of providing assistance services in-house.

Fashion Freaks – Remade, Recycled, Revisited 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, descriptions of how to modify ready made garments and much else - all to suit wheelchair riders. *Fashion Freaks* was one of several services that moved to its own homepage during the year. Its English and Swedish versions, fashionfreaks.se and en.fashionfreaks.se, together received about 10,000 unique visitors per month on an average in 2012.

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 2012 to be the first search result for “Independent Living” in Google.

Completed projects

Accessible Vacation Home Exchange, our online referral service has been our contribution to promoting travel abroad for persons with extensive disabilities. Our online service enabled

persons interested in home swapping to find interested partners by posting descriptions of their homes that are relevant for accessibility and usability by other persons with extensive disabilities. The service underwent an upgrade two years ago resulting in improved appearance and additional functions. Yet the service coded in CMS Drupal contained serious security leaks and was vulnerable to spam which entailed high maintenance costs. Thus, the service without financing of its own and maintained by volunteer Miles Goldstick had to be closed.

Participation in other organizations' events

ILI staff members took part in the following events

- December 20 lecture on "Independent Living and the Social Model of Disability" for the Occupational Therapy Curriculum at Karolinska Institutet, Stockholm
- November 13 panelist at seminar on "How Civil Society Can Be Instrumental in Implementing Human Rights" organized by Equality Ombudsman, Human Rights Days Gothenburg
- June 19 invited presenter "Personal Assistance empowers persons with disabilities and benefits the national economy" at Journada FEKOR, Bilbao, Spain
- May 23-25 invited presenter "Personal Assistance and the Crisis: Now is the time to promote Direct Payments for Personal Assistance." Invited paper presented at the Congress of the European Spinal Cord Injury Federation, Lucignano, Italy
- May 14 lecture on "Independent Living and the Social Model of Disability" for the Occupational Therapy Curriculum at Karolinska Institutet, Stockholm
- May 7 "Personal Assistance: Key to Independent Living as illustrated by the Swedish Personal Assistance Act" Invited paper presented at Colloquium "CRPD and EU Structural Funds: The way ahead for Independent Living", United Nations Human Rights, Office of the High Commissioner, Europe Regional Office, Brussels
- March 30 Civil Society Council meeting at the Equality Ombudsman
- February 14 invited presenter at conference "The Hidden Power: We make Enterprises Grow" organized by SAMHALL
- January 22-23 "Personal assistance policy features for Independent Living: the Swedish Personal Assistance Act of 1994 as illustration", Keynote for workshop at World Future Council conference "Good Policies for Persons with Disabilities", Vienna, Austria

ILI's staff published

Berg, Susanne "Transcription and translation of seminar with Bizchut for project "*Using the Law as Tool for Social Change (Med lagen som verktyg)*" 2012-01-25"

Two chapters in Brusén, Peter, Flykt Karin (eds.) "Perspektiv på personlig assistans", Gothia Förlag Stockholm 2012: Ratzka, A. Chapter 2 "Independent Living-rörelsen banade vägen"; Berg, Susanne. och von Axelsson, Hans. Chapter 9 "Framtidsperspektiv på assistans"

Adolf Ratzka "Message to young people" interview by Peter Lambrechts in Brussels on May 8, 2012 produced by Katleen Deruytter available on YouTube

Over the years a number of English texts by Adolf Ratzka have been translated and published in other languages. Websites with translated texts we found so far include:

- Catalan www.diba.cat/c/document_library/get_file?uuid=90507a0c-82f5-45e7-b3ec-436f6b52b6b8&groupId=527890
- French <http://membres.multimania.fr/maller/Definition/assistance.htm>
- German www.freak-online.at/freak-online/aktuell/aktuell-detail/article/selbstbestimmt-leben-in-europa-kopie-1/
www.forsea.de/cgi-bin/search/search.pl?Terms=ratzka&suchen=Suchen
- Greek Autonomia Greece www.disabled.gr/cgi-bin/search/search-disabled.cgi?q=ratzka&form=extended&x=13&y=12
- Italian ENIL Italia **Fel! Ogiltig hyperlänkreferens.**

- www.agenziavitaindipendente.venezia.it/images/stories/modulistica/manuale.pdf
- Japanese
http://books.google.se/books?id=XPG_MAAACAAJ&dq=inauthor:%22Adolf+Dieter+Ratzka%22&source=bl&ots=h28aP6mKXC&sig=tv8wOJvs1gz4bMgOO7LUXQDRX_Y&hl=sv&sa=X&ei=DZN2UPvGG6uQ4gSt5YHoAQ&ved=0CEUQ6AEwBA
Gendai Shokan Co., Ltd., 2-2-112 Misakicho Chiyoda-ku, Tokyo
- Portuguese www.sociedadeinclusiva.pucminas.br/sem4/082.pdf
www.orkut.com/Main#Community?cmm=22006983&hl=pt-BR
- Slovak **Fel! Ogiltig hyperlänkreferens.**
- Slovenian YHD, Association for Theory and Culture of Handicap www.handyworld-si.com/
- Spanish www.asoc-ies.org/vidaindepen/docs/mvi_exper_internac.pdf
http://diversidadfuncional.blogspot.se/2008_02_01_archive.html
www.disabilityworld.org/09-10_03/spanish/vida/sweden.shtml
<http://ebookbrowse.com/movimiento-de-vida-independiente-pdf-d368538725>
- Swedish www.independentliving.org/libauth.html

Study visits at ILI

- November 29 Mr Akihiro Sunaga, Managing Director, The Japan Institute of Scandinavian Studies, The Japan Sweden Foundation, Tokyo, Japan
- October 3 – 8 Ms Anieke Fimmen, attorney and Ph D student School of Law, Freie Universität Berlin, Germany
- September 3 Professor Tamada, Zokei University, Tokyo, Japan and students Ms. Nozomi Nishino and Ms. Manami Tamada
- August 27 “Disabled Youth Dream Team”, Byulbaragi, Republic of Korea
- July 24 JiHye Ahn, Sookmyung Women's University, Republic of Korea.
- July 13 Bala Raju Nikku, visiting lecturer at Universiti Sains, Malaysia
- July 9 Professor Yutaka Takamine, Department of Human Sciences of the Faculty of Law and Letters, University of the Ryukyus, Okinawa, Japan and five graduate students
- July 2 Mina, student of Social Affairs, Daegu University, Seoul, Republic of Korea
- June 9 Ms Anne Sinnott, Research Fellow, University of Otago, Christchurch, New Zealand
- February 20 Prof Toshiro Tamada, Zokei University, Tokyo, Japan and Ms. Emiko Tanaka, lecturer in Social Work at Tokyo Kasei University with 20 students
- January 30 Eunice, Ya-Yu Kao, Ph D student National Yang-Ming University, Institute of Health and Welfare Policy, Taiwan currently University of Jyväskylä, Finland
- January 26 Ms Esther Sivan, Director, Bizchut, The Israel Human Rights Center for People with Disabilities, Jerusalem, Israel

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 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, experts or may regard individuals looking for support and advice. Currently we spend on average almost 30% 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 been

- Overseas Editor and peer reviewer for the scientific journal “Disability and Society”, UK
- Distinguished Fellow “The Review of Disabilities Studies”, Center on Disability Studies, University of Hawaii
- Member “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, January 2012, Vienna
- Board Member STIL, Stiftarna av Independent Living i Sverige

ILI staff

- **Susanne Berg** has shared the position of ILI’s Director with Adolf Ratzka since September 2010. She works with the pilot study *Med lagen som verktyg* “Law as Instrument for Social Change” and project *Fashion Freaks*. She works part-time.
- **Philip Day** continues part-time as database programmer working with among other projects *Assistanskoll* where he participates in developing the service, runs Equality Ombudsman Reporting Service and maintains the various catalogs on our homepage such as *Study and Work*.
- **Davy Gaeremynck** worked part-time with administration, accounting and selling advertising space on Assistanskoll’s homepage until December 2012 when he left our organization to concentrate on his own translation and consulting business. We miss his wide competence and dry humor.
- **Miles Goldstick** works as volunteer with the *ILI Library* and our Accessible Vacation Home Exchange service.
- **Algren Morgan** is administrator for *Assistanskoll*, updates contact details for service providers and municipal case managers and contributes to the service’s development.
- **Adolf Ratzka** shares ILI’s directorship with Susanne Berg. He works part-time.
- **Minna Nyman Sabbadini** worked part-time as journalist with *Assistanskoll*, in particular, when Kenneth Westberg was on parental leave..
- **Kenneth Westberg** works part-time as journalist with editorial responsibility for *Assistanskoll* incl. newsletter, interviews, news, guides and manuals, reference library with facts and figures. He also contributes to the service’s development.
- **Meagan Whellans** has coordinated project *Fashion Freaks* since April 2011.

Funding

We thank

- STIL, Stockholm Cooperative for Independent Living (the Swedish name has been changed to Founders of Independent Living in Sweden or Stiftarna av Independent Living i Sverige) which contributed to ILI’s activities with work space and financial support.
- ULOBA for its financial support which is used for, among other things, to publish articles in English on the situation of personal assistance users in Europe.
- The Swedish Inheritance Fund which financed the pilot study *Med lagen som verktyg* (*Law as Instrument for Social Change*) and *Fashion Freaks*.

In addition, ILI:s activities have been financed by advertizements on Assistanskoll.se

Board composition and meetings

Kalle Könkkölä, Helsinki, 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 much more.

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

Bente Skansgård, Oslo, started ULOBA, the Norwegian counterpart to STIL in Sweden, former president of ENIL, former local government politician, worked during the 1980's at Norwegian Building Research Institute where she researched housing issues.

Adolf Ratzka, Stockholm, 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 ILI since 1993.

The Board had its annual meeting on July 27, 2012 as well as periodic contacts by mail and telephone.

Stockholm 22 March 22, 2013

Kalle Könkkölä

Kapka Panayot

Adolf Ratzka, chair

Bente Skansgård