

Ongoing activities

After project [Assistanskoll's](#) (approximately “control over your assistance”) financial support by the Swedish Inheritance Fund Commission (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 updating 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. Up to the end of 2011 214 private assistance providers had joined [Assistanskoll's](#) provider comparison. These providers together served a total of 8,235 customers/members which represents approximately 75% of the Swedish private 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 4,600 email addresses of which approximately 350 are assistance providers and 950 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 different levels. [Assistanskoll's](#) homepage had 69,000 unique visitors (66,000 in 2010). The exposure has made [Assistanskoll's](#) homepage and newsletter an interesting forum also for advertisements which cover the lion's share of Assistanskoll's running costs. Among the year's improvements of Assistanskoll's provider comparison service was our Transparency Index (TI), an index that measures a provider's willingness to disclose information such as the amount available for a customer's administrative expenses, for example, accompanying assistants' travel costs or information about the provider's administrative costs and profits.

[ILL'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 150 in Swedish and several 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 visits per year.

The [Discrimination Ombudsman Reporting Service](#) (Swedish language) assists individuals and organizations in reporting discrimination to the office of the Discrimination 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 DO Reporting Service has not had its own funding and we are looking for a more sustainable financial solution.

[Accessible Vacation Home Exchange](#) is our contribution to promoting travel abroad for persons with extensive disabilities. Our online service enables 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 some time ago resulting in improved appearance and additional functions. While we have not been overly energetic in marketing the free service in 2011 over one hundred websites refer to [Accessible Vacation Home Exchange](#) which Miles Goldstick currently attends to on a volunteer basis.

[ILI's homepage](#) continued also in 2011 to be the first search result for "Independent Living" in Google among a total of almost 11 million. The homepage had a total of 112,337 unique visitors in 2011
New Project

"With the Law as Tool for Social Change" ("Med lagen som verktyg") is the title of a pilot study whose application was submitted to the Swedish Inheritance Fund Commission (Allmänna Arvsfonden) in October 2010. After a positive decision a year later work with the project began in December 2011. The study is to look at the feasibility of and the requirements for a larger project which would build up legal expertise among Swedish disability organizations on discrimination on the grounds of disability. The objective is to better utilize existing legislation and legal praxis at the Swedish, European, EU and United Nations level for defending the human and civil rights of persons with disabilities. A number of NGOs abroad that we have cooperated with over the years serve as role models for the initiative. The pilot study will end in fall 2012.

Completed project

Project [STEPS \(Stimulate entrepreneurship in the provision of social services for people with disabilities\)](#) was started in August 2009 and finished in June 2011. Our partners in this two-year project financed by the European Union's Leonardo Program were [ADO Icarus](#), Belgium (lead partner) and [Inima de Copil](#), Romania; Association [Friends of the Home for Children](#), Bulgaria; and Academy of Management, Poland. The project was to stimulate a wide pan-European exchange of expertise among the partner organizations in former Eastern Europe and Belgium and Sweden through joint seminars and mutual study visits. ILI hosted a seminar in Stockholm in 2010 and participated in study visits and workshops in Flanders, the Netherlands and Romania with presentations on [de-institutionalization](#) and [users' self-determination](#).

Participation in other organizations' events

ILI staff members took part in the following events

- December 19 lecture for Occupational Therapy curriculum, Karolinska Institutet, Stockholm
- November 3 lecture for patients and staff at Princess Marina Hospital, Gabarone, Botswana
- September 27 lecture about Independent Living at [Funkanu](#), a Swedish web access company
- June 17 lecture at Uloba Seminar in Oslo on the United Nations Convention on the Rights of Persons with Disabilities and its impact
www.uloba.no/aktuelt/arkiv/Sider/FN-konvensjonen-og-oss.aspx
- June 16 lecture at [Uloba Seminar](#) in Oslo about Personal Assistance in connection with ULOBA's 20 year anniversary
- May 29 conducted workshop in Reykjavik for board of [NPA](#), Iceland's first personal assistance user cooperative
- May 28 participated in hearing in Reykjavik with members of the Icelandic Parliament's commission drafting personal assistance legislation
- May 28 lecture about peer support at membership meeting [NPA](#), Reykjavik, Iceland's first personal assistance user cooperative
- April 12 meeting at the Office of the Discrimination Ombudsman, Sweden on the role of Civil Society in combatting discrimination

Publications

ILI's staff was involved in the following publications.

- Assistanskoll published 61 articles (most in Swedish) during the year containing interviews with personal assistance users, politicians, lawyers, civil servants in public agencies and representatives of civil society. An additional 41 articles were published on Assistanskoll's [homepage](#) about various aspects of personal assistance such as legislation and its interpretation by the Social Insurance Fund (Försäkringskassan), other government agencies and the courts, personal accounts by assistance users, etc.

- Assistanskoll's newsletter was published 12 times during the year with summaries and links to the latest articles on Assistanskoll's homepage as well as information about the service providers taking part in our comparative consumer service.
- Assistanskoll's reference library with facts and figures continued to grow with legal texts, regulations, recommendations from government agencies, government studies, dissertations and papers, media coverage, etc.
- Over a dozen articles in the [blog Fulldelaktighet](#) (Swedish for "full participation") which also were published in a book with the same title.
- Keynote presentation "[Personal responsibility as precondition for personal and social change](#)" was published in Proceedings of the Second International Conference on "Personal Responsibility on the Way to Social Change [Jerusalem Center for IndependentLiving](#) December 2, 2010 also available at [www.independentliving.org/node/1169](#)
- Preface to "Free", [a book of photographs](#) about Independent Living published December 2011 by NPA, the first Icelandic personal assistance users cooperative.
- Keynote address "[Independent Living for People with Disabilities of All Ages](#)" at the [NNDR - 11th Research conference Reykjavik, Iceland, May 27 - 28, 2011](#) also available at [www.independentliving.org/docs1/personal-assistance-all-ages-Reykjavik.html](#)
- Contribution to [World Report on Disability](#) 2011 as peer reviewer and "additional contributor" published by the World Health Organization and The World Bank
- "Half a century with a disability: personal reflections" in webzine [StigmaVakt](#), Norway
- The Newsletter of ENIL, the European Network on Independent Living, republished in the series "Independent Living Classics" A. Ratzka, "[Independent Living for people with disabilities: from patient to citizen and customer](#)", keynote address given in Barcelona 22 October 2007.

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](#)

Invitations with fully paid expenses which we could not follow

November 18–20 São Paulo City, Brazil as presenter on the impact of the International Year of Persons with Disabilities (1981) at the International Workshop To Celebrate 30 Years Of The IYDP: A journey Of People With Disabilities Towards Full Citizenship organized by the State Department Rights of Persons with Disabilities of the State of São Paulo.

Study visits and deliberations

- November 28 in cooperation with [Access Sweden](#) deliberations with airline SAS regarding handling of power wheelchairs at airports
- November 25 Prof Clemens Fischer with 20 students from Edith-Stein-Institut für soziale Berufe (institute for social professions) Rottweil, Germany
- September 23 Michele Scheib, [Mobility International USA \(MIUSA\)](#) visits ILI for deliberations about cooperation
- June 2 meeting with [Chris Palames](#), Massachusetts
- June 1 meeting with [Elaine Ostroff](#), Massachusetts
- April 28-29 NGO "League for Vital Help to People with Developmental Problems", St. Petersburg, Russia for study visit and seminar at ILI. See [report](#) and article in [St Petersburg daily newspaper](#) and Russian national daily [Izvestia](#)
- March 16 researcher Alessandra Grotta, Milano visits ILI
- February 10 regional officers of the [European Network on Independent Living](#) visit ILI
- February 10 Professor in Social Work from South Korea and South Korean Embassy staff visit ILI

Other professional contacts

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 50% 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 "[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, well-known Swedish Disability Movement and Disability Studies profile, writer and debater, has earlier worked for ILI projects [Radio Independent Living](#) and [Fashion Freaks](#) and shares the position of ILI's Director with Adolf Ratzka as of September. She works part-time.
- Philip Day continues as database programmer on part-time working with among other projects [Assistanskoll](#) where he participates in the development of the questionnaire, [Discrimination Reporting Service](#) as well as with maintaining the various catalogs on our homepage such as [Study and Work](#). He is also seconded to the Spinalis Foundation where he works with their project [Spinalistips](#).
- Davy Gaeremynck works as part-time administrator.
- Miles Goldstick works as volunteer with the [ILI Library](#) and our [Accessible Vacation Home Exchange](#) service.
- Algren Morgan continues as administrator for [Assistanskoll](#) where he is responsible for contacts with service providers and municipal case managers and participates in further developing our questionnaire.
- Adolf Ratzka shares ILI's directorship with Susanne Berg. He works part-time.

- Kenneth Westberg continues his part-time position as journalist for [Assistanskoll](#) where he is responsible for newsletter, interviews, news, guides and manuals, reference library with facts and figures. He also participates in further developing the questionnaire.
- Meagan Whellans has coordinated project Fashion Freaks 2.0 since April 2011.

Sponsors

We thank

- [STIL](#), Stockholm Cooperative for Independent Living (the Swedish name has been changed to Founders of Independent Living in Sweden) which contributed to ILI's activities in the form of physical work spaces and financial support. The support was used for among other things project Ta Plats! and for preparing a network of experts on accessible public transportation.
- ULOBA for its financial support which is used for, among other things, to start up a network of experts on personal assistance.
- International Programme Office for Education and Training ([Internationella Programkontoret](#)) which made our participation in project STEPS possible.

Board meeting

The Board had its annual meeting on June 17, 2011.

Board

Kalle Könkkölä

Kapka Panayot

Adolf Ratzka, chair

Bente Skansgård