

ANNUAL REPORT 2022

Independent Living Institute (ILI) works to promote opportunities for persons with disabilities for more personal and political power, self-determination, full participation and equality through information, education, advocacy, and project activities. In 2022, ILI carried out several projects in pursuit of its goals and visions, described in this document. All major projects have their own webpage, Facebook page, and published newsletter.

The structure of this annual report is as follows: 1) project activities, 2) other ongoing activities and information about the institute, including a list of events, news articles, consultation responses, etcetera which have been carried out/produced during the year, as well as lists of the office staff, board members and received funding.

PROJECT ACTIVITIES

Anmälningstjänsten (The Disability Discrimination Reporting Service)

Anmälningstjänsten helps individuals, and organizations report discrimination cases to the Equality Ombudsman and, where applicable, to the respective municipal building committee. The service has been developed and has existed since the late 1990s. During 2022, the site had approximately 3,000 visits from some 2,500 individuals who made 27 claims (more than in 2020 but less than in 2021). The service was administered through funding from the Swedish Inheritance Fund via the project Article 19 as a tool during its project period.

Article 19 as a tool (Artikel 19 som verktyg)

The project Article 19 as a tool started in 2019 and ran until the end of March 2022 through funding from the Swedish Inheritance Fund. The project was managed through dialogue with an active and competent reference group and the steering group of representatives from ILI and the Raoul Wallenberg Institute of Human Rights and Humanitarian Law (RWI).

During 2022, the work has been based on the previously established main tracks: 1) raising rights holders' awareness of their rights, 2) finding methods to enable the follow-up of how well Sweden complies with its international obligations, and 3) developing legislative proposals for better implementation of the commitments. Jamie Bolling has been the project manager since September 2021.

Various activities have been carried out with partner municipalities and civil society organizations. These include training, discussion groups on Article 19 and the situation of the rights holders, study circles and policy development and consultation responses to government bills. ILI and the project Article 19 as a tool have also contributed to civil society's parallel reporting to the UN on the Economic, Social and Cultural Rights.

Information has been continuously developed through articles and posts on the website – lagensomverktyg.se – and social media. The legal gap analysis is developed and available on the website with the following finished products: the study material, the follow-up tool and the self-determination barometer, and the PA guide with tips on recruiting personal assistants. The counseling service has continued to attract individuals on a regular basis. Around 50 new cases were registered with the project during 2022, and several of these as well as earlier cases, have been active through recurring contacts.

The project website had 22,000 visits from 19,000 individuals in 2022. The website is shared with the former project Law as a tool (Lagen som verktyg). The Facebook page Article 19/Law as a tool had 594 followers, and the newsletter had 281 subscribers and three issues during the year. Five mini-seminars have been published on Youtube.

Assistanskoll

After Assistanskoll' 's project period and its funding through the Swedish Inheritance Fund ended in 2010, the web service has continued to increase in content and scope. Assistanskoll offers information, analysis and advice to assistance users, their families and personal assistants on the choice of assistance provider. Personal assistants are informed of salary levels, collective labor agreements and terms of employment. LSS- officials can, through Assistanskoll, provide information to assistance users and their families. Assistanskoll keeps the public updated on legal changes, the political game around assistance, legal precedents and market developments.

At the end of 2022, 173 assistance providers participated in Assistanskoll's comparison service (170 non-municipal and three municipal). In addition, 35 assistance providers that have not provided information are listed. Assistanskoll's website had approximately 600,000 page views during the year (675,000 in 2021). This exposure makes Assistanskoll's website and newsletter an interesting forum for advertisers, which nowadays covers Assistanskoll's operating expenses.

Assistanskoll's newsletter, edited by Kenneth Westberg, is published around once a month and has achieved a market-leading position in monitoring developments within personal assistance in Sweden. Our articles and other information are often quoted. The newsletter reaches 4,300 email addresses. The target groups are assistance users, their relatives and assistants, assistance providers, disability organizations and their publications, unions, LSS – officials, government officials and politicians at all levels.

Assistanskoll contains a large number of information pages and guides. Popular pages are, for example, our comparisons of collective labor agreements, the guides: Working as an assistant; Compensation for work during unsocial hours for personal assistants; How much is the salary for personal assistants?; Recruiting personal assistants; Organize your own assistance; and Prepare yourself for your assistance assessment.

Assistanskoll has a webpage with comprehensive statistics on the number of individuals entitled to personal assistance, grants/rejections, costs for assistance, and the number of assistance users who have chosen providers that are private companies, municipalities, cooperatives, etcetera.

Examples of activities at Assistanskoll's website during the year:

- We have reported on the run-up to the national election in September 2022 and the ongoing Parliamentary inquiry on national or municipal mandatorship for personal assistance.
- We have documented facts on assistance providers that have lost their operating permit from IVO in a more thorough way and which of these are currently operating under a stay of execution.
- 130 news articles on personal assistance have been published on the website.
- Two columnists: Nora Eklöv and Thomas Juneborg, write regularly at Assistanskoll.

The DI-project – a paper on deinstitutionalization

With funding from the Grant Foundation (Bidragsstiftelsen), ILI is carrying out a project against institutionalization since November 2020. Within the project, a paper is produced in English and Swedish, "The freedom to choose with whom, where and how you want to live: deinstitutionalization (DI) in Sweden".

The publication describes the history of and processes around the closing of institutions in Sweden. The publication also describes the importance of support services under LSS, the work of the Independent Living Movement and the development of personal assistance. This work was important for the Swedish reform at the closure of large institutions as the support was regulated under the legal reform of LSS and provided personal assistance. The publication highlights present days challenges with risks of institution-like working methods and re-institutionalization. The publication was completed and launched during spring 2022 but has since been updated, and a new edition and an English translation will be launched in January/February 2023.

Disability Rights Defenders (DRD)

Disability Rights Defenders is a network of individuals and organizations interested in rights and legislation concerning people with disabilities. Bente Skansgård's Independent Living Fund funded the project. The overall purpose of the network is to promote access to rights for persons with disabilities on equal opportunities with others. The network disseminates and deepens expert legal knowledge of rights for persons with disabilities, disability organizations, lawyers and legal education. The ability to use the law as a tool is strengthened by the mutual sharing of legal knowledge. We do this by bringing people together in our Facebook group, "Disability Rights Defenders".

In 2022, the Facebook group had 2,330 members from more than 1200 countries. Members share their experiences, methods and how they use the law as a tool. The content of the Facebook group is summarized in a newsletter a couple of times per year. Webinars have proven to be a successful way to disseminate information on DRD and rights and legal processes. DRD was active within the European Network on Independent Living (ENIL) and participated at a side-event meeting under COSP on deinstitutionalization in June. A digital meeting with the Nordic Independent Living Movement on deinstitutionalization, personal assistance and the implementation of the CRPD took place in November.

Disabled Refugees Welcome (DRW)

Disabled Refugees Welcome was an integration project carried out between 2017-2020 with funding from the Swedish Inheritance Fund. The activities are continued on a smaller scale within ILI and through new project cooperations built on the experiences from DRW (see below on the cooperation with DHR, Lithuanian Disability Forum and UNHCR). The purpose of DRW was to develop new methods that produce better conditions for the reception and integration of newcomers and migrants with disabilities. During the project period, the needs of the target group were documented, and a number of activities were developed that, in the future, can become a natural part of the Swedish system for the reception of migrants. DRW's methodological material: the information handbook, "Roads to mutual integration", and the method handbook, "Welcome whoever you are", collects DRW's conclusions, the target group's needs, analysis of the situation and measures needed to achieve mutual integration. The material has been spread during the year to be used by various actors working with DRW's target group.

ILI maintains contact with the target group, and persons who contact the project for support/advice have been referred to other actors or the project, "Mutual integration and the right to work" (RTA), depending on the nature of the case.

DRW/DHR on the integration of migrants with non-normative abilities

The project, Integration of migrants with non-normative abilities, is a cooperation with DHR funded by the Grant Foundation (Bidragstiftelsen). It started in October 2021 and continues until September 2023. The project aims to promote the integration of migrants with non-normative abilities through developing knowledge and sharing experiences on the double competence: disability and integration issues and through the target group's inclusion in civil society. A checklist is being produced on how organizations can increase diversity through the inclusion of more migrants with disabilities within their activities.

Migration and disability – cooperation DRW/UNHCR/Lithuanian Disability Forum

During 2022, DRW/ILI carried out a series of seminars in cooperation with the Lithuanian Disability Forum with funding from the UNHCR Representation for the Nordic and Baltic Countries. The seminar series aimed to disseminate knowledge of migration and disability and experiences from the project Disabled Refugees Welcome and improve the reception of migrants with disabilities in Lithuania.

Five webinars, with approximately 25 participants each, were carried out. The training/seminar series included information on Independent Living, CRPD, models on disabilities, experiences and results from the DRW project and good examples from Sweden of work in migration and disability. The cooperation's conclusions are that there is now an increased awareness within the area and better preparedness to receive the target group to Lithuania.

Mutual integration and the right to work (RTA)

In April 2022, the project, Mutual integration and the right to work, started, funded by the Swedish Inheritance Fund. The project is built on the experiences from the earlier project DRW – Disabled Refugees Welcome, but now focussing on work.

The purpose of the project is to improve the integration process, as well as increase employability among migrants with disabilities, and bridge the obstacles which the target group encounter entering the labor market on equal opportunities as others.

The project is connected to integration networks and networks around disability rights around the country. The experience has shown that integration networks lack a disability perspective and the networks around disability rights lack an integration perspective this based on the experiences of people with a migration background that the project has interviewed. The project contributes to increasing awareness of intersectionality, disability perspective, rights perspective, empowerment, participation and mutual integration within existing networks. Connecting people has proven to be effective and has led to new and important collaborations. Developing a network of actors who are willing to offer internships, assignments and hire from the target group is one of the main goals. Awareness-raising and knowledge-raising work has been of decisive importance for both the project's primary and secondary target groups.

The project has 11 goals and has largely produced the expected results and, like all projects, has produced new ideas and new development. With the new circumstances in Sweden, the work has developed to include people who fled from Ukraine, which was not intended when the project application was written because it was before the start of the war. The project has contact with people from Disabled Refugees Welcome, but many new people have contacted the project and the collaboration has developed with many new organizations.

In 2022, the website had 5,500 visits, and the Facebook page had 524 followers. The website and Facebook page of Disabled Refugees Welcome have been revised and are now used by the right-to-work project (i.e., the same number of visits and followers). Eight newsletters with 25 articles and news items, etcetera, have been sent out during the year. Information material has been produced and disseminated to the target group of the project and various actors within the area.

TRIPS

The Independent Living Institute (ILI) participates in an EU project called TRIPS - TRansport Innovation for disabled People needs Satisfaction. The goal of the project is to improve the transport systems for persons with disabilities in Europe. ENIL, the European Network on Independent Living, is the project partner, and ILI is a sub-partner with Stockholm as the project area. TRIPS is a 3-year project, from February 2020 to January 2023, with 7 European cities taking part: Bologna, Brussels, Cagliari, Lisbon, Sofia, Stockholm and Zagreb.

TRIPS brought together various persons in so-called "co-production groups" in each city. Within these groups, persons with disabilities, transport providers, municipal officials and others involved within the transport sector cooperate to jointly find solutions to how transport can be made more accessible. During the year, TRIP's Stockholm group contacted several actors to spread information about the project. A cooperation project with funding from Vinnova was carried out through Lund University, which can carry on the work done by TRIPS in Sweden (see below). An application for cooperation within K2 has been granted, and the project starts in 2023.

TRIPS/Digital travel support within public transport for travelers with a variety of needs

Digital travel support within public transport for travelers with a variety of needs was a project funded by Vinnova and carried out in cooperation with Lund University and Malmö University. The project goal was to increase accessibility within public transport to produce changes in behavior so more persons chose to travel by public transport for more sustainable mobility and healthy travel patterns. The project started on 1st November 2021 and went on until 1st May 2022. Part of the project consisted of finding more cooperating partners to carry out a longer project with the same goal. However, the application for this project was denied. Various other ideas led to more project applications, of which the cooperation K2 was granted.

Other ongoing activities and more about the institute

The library, the PA-network, PA-tips and Fashion Freaks

ILI's online full-text library offers authors the publication, exposure, and secure archiving of their work, such as articles in scientific journals, reports, handbooks, and lectures on Independent Living and related topics. Currently, the searchable library contains just over 600 documents, of which the majority are 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 the British researcher M. Miles asked us to publish, about the treatment of people with disabilities in Asian cultures.

Fashion Freaks - your online rehearsal room is about fashion, clothing and vanity from a seated perspective. Fashion Freak's basic idea is that people in wheelchairs are as vain as everyone else. We are all unique persons with the right to our own tastes and style. At the same time, finding stylish clothes sewn for "sitting" shapes is almost impossible. Fashion Freaks is a wardrobe full of basic custom patterns, sewing instructions, descriptions of how to customize ready-made clothes and much more - all to suit wheelchair users. Fashion Freak's website, available in Swedish and English, previously had project support from the Swedish Inheritance Fund and has continued to have many visitors to the site, about 250 people per day, half of whom are from Sweden.

The law as a tool was a project funded by the Swedish Inheritance Fund that finished in 2019 but whose operations have continued to some extent since. The project worked to increase the disability movement's access to legal expertise with the purpose of better ensuring the rights of persons with disabilities. The method was that law as a tool and case law counteract negative and structural discrimination. The project lives on, for example, through the website, which has been further developed through the project Article 19 as a tool. As a result of the project, several organizations still refer persons to the ILI for legal counseling or search for juridical support to carry out individual court cases.

The PA-network disseminates information about personal assistance in Sweden through articles and summary texts in English and information about the situation for assistance users in other countries. Although most of the materials are getting older, there are still appreciative comments from readers. Communication with readers also includes advice based on the content of the articles.

PA-tips.se (personal assistance tips, formerly Assistance tips) is a large collection of tips, tricks, and examples (with text, images, videos, or drawings) that assistance recipients and their assistants have developed for various assistance situations. The project had previous project support from the Swedish Inheritance Fund

Organization of conferences/seminars/study visits/training activities and participation in events organized by others

During the year, a number of conferences, seminars, study visits and training activities were organized. ILI staff also participated in events organized by other organizations/actors. A selection is listed below:

- 13/1 Kickoff Work packages 5 and 6 with the TRIPS project on the Future mobility of persons with disabilities.
- 26/1 Presentation "Independent Living and Personal Assistance" at ENIL's PAKT project webinar.
- 2/2 Disability Rights Defenders Nordic Network meeting.
- 11/2 Mini-seminar launching the study material on Article 19 and the CRPD. This mini-seminar was the first of five seminars in a series launching the end products of the project Article 19 as a tool.
- 15/2 Dialogue meeting with the project Min sexualitet - min rätt (My sexuality – my right).
- 16/2 Jamie Bolling was speaker representing ILI at Global Disability Summit - World Independent Living Center Network (WIN) side event.
- 17/2 Mini-seminar launching the Self-determination barometer. The mini-seminar was the second of five seminars in a series launching the end products of the project Article 19 as a tool.
- 23/2 Study visit at ILI from Egenmaktsgruppen (the empowerment group) in Partille, Autism Sweden (formerly the Autism och Asperger Association) and Attention.
- 4/3 Mini-seminar launching the PA guide. This mini-seminar was the third of five seminars in a series launching the end products of the project Article 19 as a tool.
- 9/3 Mini-seminar launching Self-Assessment Tool for Duty-Bearers and Rights-Holders. This mini-seminar was the fourth of five seminars in a series launching the end products of the project Article 19 as a tool.
- 11/3 Opening of the Photovoice exhibition (ongoing March - April) at the Multicultural Centre.
- 16/3 Mari Siilsalu presented the end products of the project Article 19 as a tool at the seminar Fokus Funktionshinder (Focus disability), which FOU NU arranged.
- 17/3 Mini-seminar launching the GAP analysis. This mini-seminar was the last of five seminars in a series launching the end products of the project Article 19 as a tool.
- 22/3 Meeting between Disabled Refugees Welcome and European Disability Forum about cooperation at the EU level on persons with disabilities from Ukraine.
- 28/3 Meeting with a representation from Israel on legislation.
- 31/3 Mari Siilsalu participated in a hearing about the Government inquiry into mandatorship for personal assistance at the Ministry of Health and Social Affairs.
- 7/4 ILI participated at the Swedish Institute for Human Rights meeting with organizations from civil society.
- 13/4 Mari Siilsalu gave a presentation on personal assistance at a webinar in cooperation with Turkish partners.
- 23/4 Photovoice exhibition at Quality Hotel.

- 29/4 The Swedish parallel report on Economic, Social and Cultural Rights was handed into the UN Committee on ESCR. ILI contributed with a summary of rights compliance for persons with disabilities.
- 5/5 The publication on DI (deinstitutionalization) was launched.
- 9/5 Participation in the HR Network's meeting arranged by the United Nations Association of Sweden.
- 10/5 Mari Siilsalu was a speaker at a seminar in the Parliament on the parallel report to the UN Committee on ESCR, which was arranged by the Swedish Foundation for Human Rights.
- 12/5 Seminar in the Parliament, " Så påverkar språket funktionsrätten - val 2022" (How language influences disability rights – election 2022) in cooperation with the Church of Sweden.
- 1/6 The Swedish Inheritance Fund published an article, " Avoid placing yourself in a position of power", where Disabled Refugees Welcome is highlighted as a good example.
- 2/6 ILI and the project Disabled Refugees Welcome – Right to work participated at Järvaveckan (the Järva week).
- 3/6 Study visit at the Swedish Agency for Participation in the project Disabled Refugees Welcome – Right to work.
- 6/6 Acting as a witness at the Oral Evidence Hearing, House of Lords, Adult Social Care Committee.
- 11/6 Picnick in the project Disabled Refugees Welcome – Right to work.
- 13/6 Training in the project Disabled Refugees Welcome – Right to work in cooperation with Coompanion on self-employment.
- 14/6 Disability Rights Defenders side event at the UN in cooperation with European Network on Independent Living:" Resisting calls to invest in institutions - a discussion with funders, policymakers and DPOs".
- 16/6 The project Disabled Refugees Welcome – Right to work, a mobile clinic in Botkyrka.
- 26/6 Jamie Bolling was a speaker at Independent Living France on Personal Assistance.
- 28/6 Dagens ETC published the debate article" Funktionsnedsatta måste skyddas mot ökade hatbrott" (The disabled has to be protected against increasing hate crimes), which ILI had contributed to.
- 29/6 Robin Heubscher interviewed ILI from Schwitterland on the model of direct payment.
- 29/6 Jamie Bolling, speaker at the" 11th European Conference on Rare Diseases (ECD) and Orphan Products - inequality in Education and Employment".
- 30/6 ILI contributed to the development of the UN guide to CRPD.
- 4/7 The project Disabled Refugees Welcome – Right to work, a course on information guidance.
- 7 - 8/7 The publication "The freedom to choose with whom, where and how you want to live – Deinstitutionalization (DI) in Sweden" was presented at the conference " Rethinking the institution and deinstitutionalization from a disability perspective".
- 12/7 Lecco conference in TRIPS - Jamie Bolling presented the work in Stockholm
- 9/8 The project Disabled Refugees Welcome – Right to work, pop-up meeting at Farsta square.
- 10/8 The project Disabled Refugees Welcome – Right to work, Golf meeting at Tantolunden in -Stockholm.
- 2/9 Meeting with SWIdeas about work and communication for persons with disabilities.

- 19/9 The first workshop within the project, Disabled Refugees Welcome – Right to work, on training about rights for migrants with disabilities in cooperation with partners from Lithuania.
- 20/9 Disability Rights Defenders and Jamie Bolling participated in a meeting on personal assistance in Poland.
- 21/9 ILI participated in the Swedish Institute for Human Rights network meeting.
- 26/9 The project Disabled Refugees Welcome – Right to work and the publication on deinstitutionalization (DI) were presented during the Freedom Drive.
- 26/9 The guide on PA tips was presented.
- September Presentation on "Säkerställande av tillgång till personlig assistans för äldre" (Securing access to personal assistance for the elderly) during ENIL's Freedom Drive in Brussels.
- September Presentation on "Behövs en kampanj över hela Europa för personlig assistans?" (Is a European campaign for personal assistance needed?), during ENIL's Freedom Drive in Brussels.
- 4/10 A joint seminar on the theme of disability politics and local conditions by the County Administrative Boards of Södermanlands, Västmanlands and Uppsala counties.
- 14/10 The second workshop within the project, Disabled Refugees Welcome – Right to work, on training about rights for migrants with disabilities in cooperation with partners from Lithuania.
- 28/10 The third workshop within the project, Disabled Refugees Welcome – Right to work, on training about rights for migrants with disabilities in cooperation with partners from Lithuania.
- 3/11 Disability Rights Defenders Nordic Network webinar on UN, DI guidelines and ILI's publication on deinstitutionalization.
- 7/11 Jamie Bolling participated in a hearing about the Government inquiry of mandatorship for personal assistance at the Ministry of Health and Social Affairs.
- 8/11 Study visit at ILI from the Czech Republic on the theme of personal assistance.
- 9/11 The project Disabled Refugees Welcome – Right to work was interviewed as a contribution to the UNHRC publication "Discussion Paper on Refugees".
- 14/11 The fourth workshop within the project, Disabled Refugees Welcome – Right to work, on training about rights for migrants with disabilities in cooperation with partners from Lithuania.
- 17 - 18/11 The project Disabled Refugees Welcome – Right to work participated at the Swedish Forum for Human Rights by, among other things arranging the seminar "Livet i den säkra hamnen" (Life in the safe harbor).
- 22/11 Disability Rights Defenders held a webinar on the UN guidelines for deinstitutionalization in cooperation with the European Network of Independent Living and the European Coalition for Community Living.
- 22/11 The project Disabled Refugees Welcome – Right to work held a theme day together with MISA.
- 25/11 Study visit at ILI for Disabled Refugees Welcome – Right to work from the social service administration in Danderyd municipality.
- 26/11 Training in job seeking in the project Disabled Refugees Welcome – Right to work.
- 1/12 ILI participated in the Swedish United Nations Association's planning meeting and contributed to the production of the Swedish parallel report to the Committee on the Elimination of Racial Discrimination (CERD) on the implementation of the International Convention on the Elimination of Race Discrimination.

- 9/12 The project Disabled Refugees Welcome – Right to work held a theme day together with the Swedish Outdoor Association.
- 9/12 The fifth workshop within the project, Disabled Refugees Welcome – Right to work, on training about rights for migrants with disabilities in cooperation with partners from Lithuania.
- 15/12 Presentation "Ålder och funktionsnedsättning. En blind punkt i Policy Making" (Age and disability. A blind spot in policy-making at ENIL's webinar.
- 19/12 Work café – an event for those who wanted to meet the people of the project Disabled Refugees Welcome – Right to work.
- 21/12 The final workshop within the project Disabled Refugees Welcome – Right to work, on training about rights for migrants with disabilities in cooperation with partners from Lithuania.

Publications, interviews, consultation responses, and appearances in various media

During the year, ILI's staff published news articles, text, images, and moving materials in various media.

- 130 news articles on personal assistance have been published on Assistanskoll's website during the year. Eleven issues of the newsletter have been sent out to approximately 4,298 recipients. The website had approximately 600,000 page views in 2022.
- DRW/RTA's website had approximately 5,500 visits in 2022. DRW's Facebook page had 494 likes and 524 followers. During the year, eight newsletters with 25 news articles and news items, etcetera, were sent out.
- Article 19 as a tool's website had 22,000 visits from 19,000 visitors in 2022. 58 posts/news articles were published during the year. Article 19/Law as a tool's Facebook page had 594 followers, the newsletter had 281 subscribers, and it issued three numbers in 2022.
- DRD – Newsletter was sent out to 580 subscribers. The project's group on Facebook grew to 2,330 members from more than 100 countries in 2022.

Interest-driven political moves and publications 2022:

- 6/2 Adolf Ratzka's debate article "Låt livshjälp gå före dödshjälp" (Let help to live take precedence over help to die) was published in Sydsvenskan.
- 29/4 The Swedish parallel report to the UN Committee on ESCR, where ILI has contributed with a summary of the implementation of rights for persons with disabilities, was submitted.
- 5/5 The publication "The freedom to choose with whom, where and how you want to live – Deinstitutionalization (DI) in Sweden" was launched.
- 10/5 An article about Jamie Bolling was published in the magazine Rörelse.
- 10/5 Video for an Independent Living campaign in Korea.
- 1/6 The Swedish Inheritance Fund published an article, "Avoid placing yourself in a position of power", where Disabled Refugees Welcome is highlighted as a good example.
- 28/6 Dagens ETC published the debate article "Funktionsnedsatta måste skyddas mot ökade hatbrott" (The disabled has to be protected against increasing hate crimes), which ILI had contributed to.
- 30/6 ILI contributed to the development of the UN guide to CRPD.

- September: Invitation to comment on the draft Manual of Procedures developed by the Independent Community Living Board, Agenzija Sapport, Government of Malta.
- 9/11 The project Disabled Refugees Welcome – Right to work was interviewed as a contribution to the UNHRC publication " Discussion Paper on Refugees".
- 17/11 Debate article " Sverige måste skärpa sig för att leva upp till FN-krav om rätt till arbete för personer med funktionsnedsättning" (Sweden needs to do better to live up to the UN-demands on the right to work for persons with disabilities), written by ILI in cooperation with the Swedish Disability Rights Federation and och WiljaGruppen, was published in the magazine Arbetet.
- 1/12 ILI participated in the Swedish United Nations Association's planning meeting and contributed to the production of the Swedish parallel report to the Committee on the Elimination of Racial Discrimination (CERD) on the implementation of the International Convention on the Elimination of Race Discrimination.
- 2/12 A debate article "Gör som Norge, gör funktionsrättskonventionen till lag" (Do like Norway do, make CRPD into law) was published in Altinget.

Collaboration with Nationellt kunskapscenter för dövblindfrågor (NKCDB)

Since January 2021, ILI has been part of an assembly of experts organized by NKCDB. Through a consulting assignment by Ola Linder, ILI has contributed with legal expertise, foremost in supporting the Regions' counselors on legal issues in connection to current legislation within the subject area. The assignment also includes developing an understanding of legal rights issues in general when concerning persons with disabilities.

Collaboration with the association Disability Rights Defenders Sweden (DRDS)

The association Med lagen som verktyg (MLSV, The law as a tool) was founded in 2015 on the initiative of ILI and others and is an independently operating membership-based non-profit association. The association's name was changed to Disability Rights Defenders Sweden (DRDS) at the annual meeting in 2020, inspired by ILI's project Disability Rights Defenders. The association pursues discrimination cases related to disability, if necessary, in court. In addition, the association informs about the human rights of persons with disabilities and provides advice and information about disability discrimination. ILI and DRDS collaborate on information dissemination, among other things, as DRDS' website forms part of ILI's website Lagen som verktyg and through a small administrative support.

Collaboration with the disability movement in Sweden and internationally

ILI has built up good contacts within Swedish civil society in our field through our long joint work with other organizations to expand and defend our civil rights and increase our concrete opportunities to live like others. With this broad network, we have easily found co-applicants for project applications and other cooperation. Organizations are increasingly cooperating in preparation for consultation statements and other political initiatives. We also have good international contacts through our long-standing involvement in the international Independent Living movement within Disabled People's International and ENIL, the European Network for Independent Living, and through many collaborative projects and mutual exchanges of experience.

Over the years, ILI has become an international information and contact broker, which has helped us to expand our network and deepen our cooperation with other organizations. In this way, together with many other actors, we have been able to contribute to an increased pace of development in the field of disability in many countries in terms of accessibility policies, personal assistance, assistive technology, and employment. Issues may relate to projects, literature sources, liaisons with other organizations and experts, or persons needing support and advice.

Reference groups in which ILI has participated:

- The project Funktionsrättsbyrå (The Bureau for disability rights) - The Swedish Disability Rights Federation
- The project Nothing about us without us - The Swedish Foundation for Human Rights/ Handikapphistoriska föreningen
- The project Our voices will be heard - The Swedish Disability Rights Federation, Begripsam, Handikapphistoriska föreningen.

ILI's Chair of the Board, Adolf Ratzka, has during the year been:

- Board member of the Foundation in memory of Rolf Bergfors.

ILI's Director of Operations, Jamie Bolling, has during the year been:

- ENIL's Co-Chair, member of the ENIL Management Team and Audit Committee.
- Board member of Bente Skansgård's Independent Living Fund.
- Vice Chairman of the Board of MyRight.

ILI's staff

During 2022, ILI's workforce consisted of a rich variety of skills and experience, several persons with disabilities, an even gender distribution, and a large spread in age and countries of origin. In 2022, ILI's staff consisted of the following people, most of whom worked part-time and some only for short periods:

Algren Morgan, project member of Assistanskoll.

Antwan Zolomyan, project member of the right-to-work project, from June 2022.

Erik Tillander, journalist and project member of Assistanskoll, Article 19 as a tool and the right-to-work project.

Jamie Bolling, director and project manager for TRIPS, the deinstitutionalization (DI) project, Article 19 as a tool and the right-to-work project.

Kenneth Westberg, journalist and project manager for Assistanskoll.

Linda Robertsson, Office manager, including administration, personnel and economy.

Mari Siilsalu, jurist and project member for Article 19 as a tool and the right-to-work project.

Philip Day, webmaster, database programmer and project member of Assistanskoll, the Disability Discrimination Reporting Service, Article 19 as a tool and the right-to-work project.

Rahel Abebaw Atnafu, project member of Article 19 as a tool, the DRW/DHR- project and the right-to-work project.

Selina Grießer, project manager for Disability Rights Defenders, until September 2022.

Stefan Käll, project member of Article 19 as a tool until March 2022. Stefan passed away in January 2023. som verktyg fram till mars 2022. Stefan passed away in January 2023. Read "[Stefan Käll har gått bort](#)".

Tiina Nummi-Södergren, project manager for Disability Rights Defenders and project member of the right-to-work project from October 2022.

In addition, work has been carried out on consulting basis and through short-term freelance assignments. Consultancy assignments that ran for longer periods were performed by:

Ola Linder, with assignments under the NKCDB collaboration.

Anna Bruce, Raoul Wallenberg Institute, with contributions to Article 19 as a tool.

Elena Quiñonez och Sebastian Ferrer, accounting services.

Suzanne Elmqvist, with contributions to Article 19 as a tool and the right-to-work project.

Riitta-Leena Karlsson, with contributions to deinstitutionalization (DI).

During the year, the following persons have had part of their education placed at ILI:

Ellie Lipp, 2022 Watson Fellow.

Marjan Aslanifard, Linköpings Universitet, Ethnic and Migration Studies.

Funding

Thank you from ILI to:

- The Swedish Inheritance Fund that funded the projects Article 19 as a tool and DRW – right to work.
- Bente Skansgårds Independent Living Fund that funded Disability Rights Defenders.
- Bidragsstiftelsen (the Grant Foundation) that funded the deinstitutionalization (DI) project and the DRW/DHR project on the integration of migrants with non-normative abilities
- The European Commission that funded the TRIPS project.
- Lithuanian Disability Forum and the UNHCR Representation for the Nordic and Baltic Countries that funded the project Migration and disabilities.
- The foundation Independent Living Utveckling (ILU) that contributed to ILI's activities through financial support.
- Vinnova that funded the project Digital support for public transport for travelers with a variety of needs.

In addition, ILI's activities were also funded by fees for various assignments, such as NKCDB, banner advertisements on Assistanskoll.se and private donations.

Board composition and meetings

Adolf Ratzka, Stockholm, introduced the Independent Living philosophy to Scandinavia in 1983, founder of STIL and its chairperson until 1995. ENIL's first chairperson, 1989-1992, together with Rolf Bergfors, founded GIL and the Independent Living Institute and was the director of ILI from the start in 1993 until September 2017. Adolf is the chair of the board.

Bengt Elmén, Stockholm, author, debater and lecturer. Board member of STIL and its office manager STIL 1987-1991.

Gilla Andersson, Lidingö, substitute for Bengt Elmén until 7th December 2022.

Jamie Bolling, Härnösand, human rights defender focusing on disability issues, director of ENIL 2009-2017, a former member of the Green party's national board, board member of STIL and vice chair of MyRight.

Jonas Franksson, Stockholm, human rights defender focusing on disability issues. Chair of STIL, DRDS, etcetera substitute for Bengt Elmén from 7th December 2022.

Judith E. Heumann, Washington DC, USA, one of the premier internationally recognized Independent Living activists known, among other things: for her role in the movement's 28 days occupation of the Federal Building in San Francisco that forced the Federal Government to sign Section 504 of the Rehabilitation Act of 1973; for her work at the Center for Independent Living Berkeley (where she laid the foundation of today's Disability Rights Education and Defense Fund); as promoter and Director, together with Ed Roberts, for the World Institute on Disability; as Assistant Secretary for the Office of Special Education and Rehabilitation Services, US Department of Education 1993–2001; as World Bank Group's first Advisor on Disability and Development 2002-2006; as Director, Department of Disability Services, District of Columbia; and Special Advisor on Disability Rights for the US State Department 2010–2017. Judith passed away in March 2023. Read Adolf Ratzka's text "[Judy Heumann has left us](#)".

Miro Griffiths, Leeds, UK, teaching fellow at Leeds University on disability rights issues, a researcher at Liverpool John Moores University, 2015-2018. He was awarded an MBE (Member of the Order of the British Empire) in 2014 in recognition of his services to disabled people, a member of the British Sociological Association, member of the Equality and Human Rights Commission Disability Advisory Committee, member of the Liverpool City Region Fairness and Social Justice Advisory Board, and member of the International Independent Living Research Network.

During 2022, the board had three board meetings – 17th January, 15th May and 7th December – and one per capsulam decision on 1st April. In addition, contact has been made through email, telephone and individual meetings.

2023-05-22

Adolf Ratzka

Bengt Elmén

Jamie Bolling

Miro Griffiths