

CONFERENCE REPORT

MAY 30 2018, STOCKHOLM

USING THE LAW AS A TOOL FOR SOCIAL CHANGE



By Susanne Berg

On Wednesday the 30th of May, around eighty people from a multitude of countries gathered in Stockholm to discuss litigation and other features of the law, as a possible tool for social change. The conference became an occasion, not only to celebrate Independent Living Institute's 25 years in the field but also Adolf Ratzka's time as its Director with a surprise celebration. We heard speeches about Adolf's importance for not just the Independent Living Movements but for many individuals within it. Adolf also received a gift in form of a book filled with personal memories.

The questions on the basis for the conference were:

- How can the Independent Living and Disability Rights Movement promote anti-discrimination laws and disability rights?
- What is the role of civil society in implementing Human Rights under the UN Convention on the Rights of Persons with Disabilities, the European Convention on Human Rights, and national laws?
- How can civil society use strategic litigation in this effort in the Nordic countries and elsewhere?

The morning and the afternoon of the conference each contained two sessions: one with several speakers on the subject, and one with an introductory speaker followed by a panel discussion.

The morning's theme, "The role of civil society – Human Rights implementation and strategies for legal action", started off with a session on why we need to use a legal approach fighting disability discrimination. Adolf Ratzka claimed that our organisations have been begging and pleading with the politicians and through the media. We may have won the battles but lost the war when the politicians depict us as the weakest of the weak. Therefore, a new rights-based approach is needed. An approach which will give us power, not by having laws, but by using them.

Sid Wolinsky talked about how the Disability Rights Advocates work together with the disability community using litigation as a tool to facilitate social change. On a question on representation, he described how lawyers with disabilities now are more prone to work within the disability rights area, and consequently as staff at DRA. Abbas Abbas talked about the double discrimination of Arab- Israelis and what the work his organisation, Al- Manarah is doing to change the situation, using not only the law but other civil actions.

During the second session of the morning, the conference shifted perspective to the situation in the Nordic countries. Introducing the myth of an incompatibility between the Scandinavian social consensus model and a legal approach to disability, Gerard Quinn maintained that a legal approach instead was needed to refresh the mid-century social approach. After that, a panel with representatives from the Nordic countries, Iceland, Finland, Norway and Sweden investigated the national situation in each country. During their discussion, the need to refresh the current social approach and strengthen the legal approach became evident.

The afternoon's theme, "Lawyering and litigation – how to challenge the system" started with Lena Svenaeus, the former Equal Opportunity Ombudsman presenting a way to use litigation to facilitate social change. She spoke both on strategies she used during her time as Ombudsman, and how a national institution for human rights should be set up according to the Paris Principles. She also made a case for what is lacking in the legal regulation of the Swedish Equal Opportunities Ombudsman and the consequences of this. Kapka Panayotova presented the situation in Bulgaria, where the laws are strong, but enforcement is weak as shown by cases under the Anti-Discrimination Act. Lastly, Fredrik Bergman described how the private non-profit firm, Centre for Justice work with strategic litigation and the importance of finding good cases and how they fund their work.

Cooperation and coalitions were the themes of the last session of the conference. In the introduction, Annika Jyrwall Åkerberg told how Civil Rights Defenders use other lawyers, universities and European networks to achieve more than their scant resources otherwise would allow. Ulrika Westerlund described how strategic litigation became a tool fighting for the rights of transgender people. Stellan Gärde presented the recently founded Talerättsfonden, cases this has funded and the pending strategic litigation consisting of some six or seven cases planned in cooperation with the Dyslexia Association. Sid Wolinsky described how private law firms and universities in the US cooperated with non-profit companies through scholarships and pro bono work. Issues as the how a Swedish Equal Opportunity Ombudsman should be organised and if the trade unions and the labour courts where of use, were discussed.

Paul Lappalainen moderated the conference which was sponsored by the Nordic Welfare Centre and the Independent living organisations of STIL, ULOBA and ENIL.

MORNING THEME: THE ROLE OF CIVIL SOCIETY – HUMAN RIGHTS IMPLEMENTATION AND STRATEGIES FOR LEGAL ACTION

Paul Lappalainen, moderator:



Although today is about lawyers and lawyering, for me as a lawyer, it is essential that lawyers working with causes or movements do not think of themselves as helpers. What movements should say is, “If you are only a helper we do not need you. But if you are here to learn and grow yourself, you are welcome to work with us.”

One of the persons who taught me this, when I was a helper, was Jamie Bolling. Jamie educated me in how little I knew about disability, about disability discrimination, and about the disability movement. I am proud to present Jamie Bolling.

Paul Lappalainen is an American and Swedish lawyer and researcher, specialised in discrimination law and civil society involvement.

Jamie Bolling, Welcoming words and reference to the previous two-day workshop/match “Using Law as Tool”:

It is great to see so many people here today. We are excited about this conference. We have a week with different events. Yesterday, we had a match with nine different nationalities represented and one of the recommendations where that we should build a network on litigation, which fits right into the theme of our conference today. We are celebrating 25 years of the Independent Living Institute thanks to Adolf Ratzka. Adolf had a vision, which we continue working towards.

I would also like to thank the sponsors making this conference possible: the Nordic welfare Centre, STIL, ULOBA and ENIL.



Jamie Bolling is the Director of Independent Living Institute

Session 1: Why using the law in fighting discrimination

Adolf Ratzka, introduction:

The theme of the day, using the law as a tool for social change, has been intriguing me for many years. Let us face it, we have used very many different things to improve our situation with more or less success. We may have won a battle once in a while, but the question is if we have lost the war in the process. Historically, people with disabilities and our organisations have been categorised differently individually and collectively.

In the old days of the medical model of disability, you had difficulties because there was something wrong with you, and improvement was expected to come from the medical

profession or via charity. In the medical model, disabled people beg and appeal. Then came the social model, which says that if you have a problem, it is because there is something wrong with society. Society's obstacles prevent you from becoming an equal citizen, and the solution is building a society for all through the use of universal design. In the social model, disabled people appeal, petition and demonstrate in the streets.

Our organisations have been begging and pleading, appealing to the politicians and through the media. We may have won the battles but lost the war when the politicians depict us as the weakest of the weak. We might have gained some bread crumbs, but it has not earned us power, it has not earned us respect. The most recent, and dignified way to improve our situation is the rights-based approach. Now we can act from a position of power. A power that does not come from having laws. A power that comes from using the law, from calmly being able to say, "See you in court". So let us piss on pity! Let us move the battle from the street to the courtroom!

Adolf Ratzka is a disability activist, researcher, and lecturer on independent living and personal assistance. He founded Independent Living Institute and is ENILS's founding chairperson.



Sid Wolinsky, cooperation with the disability movement as the key to finding relevant cases within disability discrimination – public interest law firms:



Disability Rights Advocate is a non-profit law firm established 1992 in Berkeley, California, the birthplace of the civil rights movements of people with disabilities. Founded by me and Larry Paradis, who sadly has passed away, DRA began with two lawyers in a borrowed office and a philosophy. We work hand in glove with community organisations of people with disabilities. We do not go off on our own. We do what groups or organisations of people with disabilities want. We do not just file a lawsuit, but work with the people from the start to the problem is solved, even if it can take a decade. We bring cross-disability actions because this builds a broader political base.

“We try to be fearless. We try to not think like lawyers, but as advocates with and for the community.” We do not look at the question of is there a legal right, but whether there is a wrong and what we can do about it. As a result, approximately 80 per cent of our lawsuits has never been brought before in the US. And we try to broaden the base of what is defined as a disability to include for example seniors and people with low vision.

Today, the Berkeley office has a staff of more than 20 people, and we own our building so rising rents cannot force us out. Six years ago, we opened a branch office in New York, which now has eight lawyers. Disability Rights Advocates has brought more than 400 major class actions since we began 25 years ago. A major focus is transport, for example, we won a lawsuit forcing 50 per cent of New York's yellow taxis to be wheelchair accessible, instead of the existing one per cent. But the problems never stop. "If you are in the injustice business, the business is always terrific." So now we are suing Uber, both in New York and California. Another area we have brought a lawsuit is the lack of provisions for people with disabilities in emergency and catastrophe plans.

Sid was asked to comment on two issues, Starbucks and representation of people with disabilities:

He refrained from commenting on the recent Starbucks case, but he answered that DRA has very good experience in dealing with Starbucks. The reason for this is, that, Starbucks is one of the very few companies that, immediately responding to DRA, when approached regarding a claim of discrimination. DRA always write and try to negotiate a solution, before bringing a lawsuit. Starbucks is now on DRA's board. Our staff changes from time to time, but we have a team representing all types of disabilities.

Sid Wolinsky is Co-founder of Disability Rights Advocates

Abbas Abbas, working with legal advice and action on multiple discrimination



Since my early age, I have heard the Arabic words yaa Haraam. “What a pity, he cannot see. He is disabled.” Unfortunately, this is the attitude most disabled people in Israel and the Arab countries meet within the family. They think disability equals shame. Fortunately, my family was different, and I could go to school and then university. My social giant awakened when I applied for a job at a human rights organisation, which did not see my professional merits at all, but only my disability. So I got down from the ivory tower if academia and started my long journey as a social entrepreneur. I founded Al-Manarah and want to share with you a video that present Al-Manarah.

From the video: Al-Manarah was established by a group of persons with disabilities under the international doctrine, “Nothing about us, without us.” It is a non-profit organisation dedicated to the advancement of persons with disabilities. It reflects values of excellence, equality and dialogue. Al-Manarah has achieved unprecedented accomplishments, and 2009 Abbas

Abbas was the first persons to receive the Ashoka Innovators for the public award. In 2013, Al-Manarah presented the paper “Doubly discriminated: disability rights for Arab persons in Israel” to the United Nations. It is the first legal and social study on Arab people in Israel showing they are denied education, employment and access to services. Al-Manarah has also won awards for its online accessible Arabic library, and the Zero project award for its thinking outside the box approach. A

particular milestone was reached when Al-Manarah gained the status as a consultant with the United Nations.

Abbas Abbas also presented the case of Houda Zoabi and upper limbs amputee, who won equal right to take a driver license and get subsidies for an adapted car, rights that existed for lower limb amputees in Israel. Al-Manarah was active with Houda's the appeal and political lobbying to change the law. The legal process in Israel is very slow, but Al-Manarah hopes to achieve success through the lobbying of legal change. Accessibility is one of Al-Manarah 's main lobbying areas.

Abbas Abbas is a Human Rights lawyer and Director at AlManarah Association Nazareth, Israel,

Session 2: Strategies for legal action and remedies in the Nordic countries

Gerard Quinn, introduction

This conference is a very nice space to reflect on legal approaches to disability. The question hovering in the background is how compatible legal approaches to disability is with your Nordic social consensus model of disability. While I gravitate towards the American civil rights approach, I have to state that the popular image if a social justice lawyer is underdeveloped in Europe. Whatever we think of lawyers and lawyering we have to remember the organic link between law and justice.

I am now working in the Raoul Wallenberg Institute at Lund's University, where we are developing a law clinic, as well as at the University of Leeds, where we are also developing a disability law clinic. As a comment on Sid's speech, class actions are not allowed in many EU countries, among them my country. I think it is time to revisit that issue since class actions reveal systemic issues. Governments need to know about these systemic issues. Another problem in Europe is that particularly university-based law clinics are severely under-developed, due mostly to restrictive rules on practice and procedures in front of the bar. We now see five to seven university law clinics emerging. Hopefully they will be doing some high-quality work, and hopefully, that will reduce the barrier to participation in the legal system.

I want to abstract three general points, from the paper I have presented at the conference. The first is the compatibility problem between legal approaches, with strategic litigation and individual litigation, and the social consensus model built up during the last sixty or seventy years. It is a mid-century approach, which need not be abandoned but rethought. I think these two approaches are compatible because, before we conceptualised disability issues as social wrongs, and now we conceptualise them also as human rights. "There is no right without a remedy. If the remedy does not exist, there is no right." To proclaim rights without remedies invites cynicism.

Secondly, there are some blind-spots in the social consensus model of disability and the politics of it. There are some inherent flaws in a politicised model of disability, or for that matter other social issues. Politics tend to forget issues or unequally promote issues, and even when politics get it right, systems atrophy and bureaucratize. The form of the rule then takes over the actual intent toward the



intended group. The legal system is different. It operationalises itself on formal logic. It interrogates the rationality of why your policies emerged, are they well-intended or not, are their impact adverse or beneficial for particular groups or individuals. At least on the surface, it is non-partisan. The absence of rationality is the problem in our disability processes, the funding, and foremost the delivery of services. So this would be a way to iron out some of the snafus and the inequities within a social policy field like that of disability.

Another way, the legal system and the social approach to disability can be compatible with each other, depends on the view of these processes. We tend to view each approach as exclusive, competing with each other, as opposites. I think this is wrong. I think they are part of a much deeper eco-system. "Litigation is not a substitute to a social consensus model of disability. It is not a substitute for a highly developed social model, which thankfully you have here in this part of the world. It is an aid." It is a tool to recognise gaps in the system, and fix faults. I would see, particularly some of the class actions as a trigger for the political process, not as a substitute for it.

A classic example is the fantastic case of *Olmstead vs LC*, which re-conceptualised our view of institutionalisation, so that, wrongful and unusual forms of segregation are discrimination. This was a big, big conceptual step for the court. We have never had a decision in Europe that in any way approximate the *Olmstead* decision of 1999. The interesting thing about the *Olmstead* case is, however, the process it started shifting the funding instruments from institutionalisation to living in the community. Leading on from that, ten years later, came the formation of the Administration for Community Living.

There are counter-arguments that opening for a more legal approach will hurt the flexibility of the social consensus model that, we would become constrained in how we work. I do not think that is true, as most of the cases, so far, do not have to do with the quantum of resources we spend on X, W or Z. Most cases have to do with queries of inequality, discrimination, and on the substance of the right. We are talking about relativity, how you are treated compared to others. When a case touches on the economy, it is usually due to other issues as integrity and autonomy. This is not to say that litigation cannot have systemic effects. The issue can be picked up by the political process and be used to make their systems more rational, more equal in outcome for individuals on the ground.

Litigation does not undermine the Swedish, or Scandinavian model of disability, but refresh it and turns it towards outcomes, which is the most important indicator. This is also how the UN looks at rights, from the perspectives of substance, process, and outcomes. Perversely enough, losing is often winning. Even when you lose, you add clarity to the issue.

Litigation is primarily about rationality and an ethic of justification. This should be what the legal system is about. Litigation, thus, helps to flush out the irrationality of the social approach. An example of this is when individuals have to pauper themselves to receive support which is a completely irrational, vicious circle. Litigation also helps the democratic system to function better, enriches it and triggers it to correct inequalities.

The Scandinavian social model of disability is a positive creation of the mid-century. It is obviously in transition. In transitioning it needs to be a blend of a traditional legalistic approach and a new commitment to a refreshed social model.

From the question time:

In his comments, Paul Lappalainen pointed out that in Sweden we often think there is a lack of remedies through the legal system, but this is not true. Powerful groups like the trade unions often use the legal approach to achieve remedies.

Gerard Quinn is Professor of Disability law and policy in Galway, Ireland, one of the architects of UN CRPD. He is associated with Raoul Wallenberg Institute in Lund.

Panel on legal conditions for the defence of disability rights; legal strategies as a complement to law reform and social development; strategic litigation as a tool for the Nordic civil society; and the Nordic systems in the European context. Findings from the national representatives:



Katrin Oddsdottir from Iceland:



Iceland is facing a huge challenge in how litigation and the courts can be used to advance disability rights. The Icelandic constitution was revised, and the human rights chapter updated in 1995. The CESCR is incorporated into Icelandic law. However, a dramatic turn of events came with a court case concerning disability benefits in 2000, which stated that disabled people could not be discriminated against on the ground of marital status. The argument was that each person owns their right. It was built on the convention and the constitution. The case created an immediate and violent political backlash based on the opinion that the courts had gone too far. Five of the judges behind the decision left the court, and new judges were appointed, by the conservative prime minister behind the backlash.

Since then we have been losing cases over and over again.

Recently Katrin Oddsdottir lost a case concerning the right to live where you choose, where the court stated that the Icelandic state did not have to follow the convention. They decided to take the case to the media, which resulted in the municipality granting the solution the client had applied for. In this way, you can say they won even though they lost in court. Otherwise, we would have had to take the case to the European court. A new law lifting the importance of the convention has recently been enacted, so there is some light in the tunnel, but Iceland need help from the international community to get back on track. At the moment, litigation is almost always back-firing, so political pressure is required.

Katrin Oddsdottir is a Human Rights lawyer at the Organisation of the Disabled in Iceland.

Jukka Kumpuvuori from Finland:

Finland is a model country on disability legislation but not on disability rights, according to Jukka Kumpuvuori. This is because of a basic feature in the Nordic welfare model, where the execution is down to some 300 municipalities, each with their instructions breaching the laws. This is why there are some 500 complaints concerning disability welfare in the Finnish administrative court system. Non-discrimination is still very much a non-issue in Finland. The Finnish disability NGOs do a lot of political advocacy, but not legal advocacy. They do not take on individual cases. Jukka agrees with Gerard Quinn that, the Nordic social model and a legal approach needs to be combined in what he calls po-legal advocacy. Finland needs even more litigations in the administrative court system and at least one proper case litigating discrimination.



Jukka Kumpuvuori is a Disability rights lawyer litigating in Finland, and before the CRPD Committee and the Court of Justice of the EU

Berit Vegheim from Norway:



Norway has this year, 2018 enacted comprehensive anti-discrimination legislation covering all grounds of discrimination. The civil society had fought to combine all discrimination grounds within one legislation, to make the rights more harmonious. The law prohibits direct and indirect discrimination, harassment and instruction to discriminate. It also sets out a duty to universal design concerning building, transport and ICT. It also contains a duty to appropriate accommodation. The movement in Norway fought to change the legal obligation from reasonable to appropriate because reasonable very often means cheap. Berit Vegheim recommends all countries to use either appropriate or effective accommodations instead of reasonable. Working for a long time on the issue of anti-discrimination legislation,

Berit claims that the main lesson from the US and the UK laws is what not to do. Therefore, the Norwegian law has an extensive definition of disability and also protects people on the grounds of assumed, future, past and connection to the ground. Berit means that what use legislation has very much depends on its wording. There are things in this legislation which never would have been there if the disability movement had not been an active part in writing it. The inclusion of a duty to universal design is unusual and important. The duty comes with legal regulations and time frames. Berit works for the foundation "Stopp Diskrimeringen", which does a lot of advocacy and teaching activities to empower disabled people. Norway has a double system with a soft law approach where you can take your case to a tribunal and a hard law approach where you can go through the court system. "Stopp Diskrimering" works with providing legal advice and advocacy, trying to get people to use the court.

Berit Vegheim is a Disability Activist at Stop Diskrimineringen and Menneskerettsalliansen

Ola Linder from Sweden:



Sweden fits well into the image painted by the other Scandinavian countries. It is not very common for people who have been discriminated against to take legal action. We have a situation where the administrative court system is filled up with appeals, particularly on the personal assistance issue. Ola Linder wonders how big the savings actually are from cutting the benefits, when also taking in the cost of the legal system. Figures on the costs for individual cases are not provided. There are several different areas of law concerning disability. The first one is the right to support and services, and the second is accessibility, discrimination, universal design and such issues related to the environment.

When it comes to the administrative court system and personal assistance, it is clear that the political system through indirect governance has changed the content of the law, even if the law itself has not been reformed. So we have people who have had their rights to services taken away, and the only remedy available is appealing through the administrative court system. This is case-based and not something you think of in a strategic manner, since the people are desperate to get necessary support back. Recently a disability organization has reported the social insurance authority to the Chancellor of Justice, that supervise whether authorities act according to legal norms or not. This seems to be the only case where the civil society has acted strategically using law as a tool in this area.

An area where the disability movement could cooperate much more concerns how to use the European convention. Can it be used as a basis to claim community-based services instead of institutionalization, which is clearly a form of discrimination under the convention? Worth to note on the administrative legal system is, that whether you win or lose you will not get your legal costs covered, making it hard for people to access legal counsel. Like Norway, Sweden has a comprehensive anti-discrimination law covering all grounds, as well as a recent clause on the lack of accessibility.

This might be a tool that can trigger municipalities to act on the common laws on building and access they are responsible for. Ola thinks the best results will come when working together with disability organizations in the same manner as Disability Rights Advocates do. A case concerning the lack of a functioning hearing loop in cooperation with the association for hearing impaired is a good example. However, in Sweden you have to sue for money, as there is no alternative.

Ola Linder is a Lawyer at Independent Living Institute's project Med Lagen som Verktyg.

From the discussion:

Sweden, Norway, Finland and Israel have equality bodies, but they are not working very well. The cases are not well argued, and their decisions not effective. Iceland does not have an equality body, and the alternative body they have is very weak.

There is a general lack of interest in law schools for disability rights, but it is slowly changing for the better in some countries. Judges are generally not educated in disability rights.

Where there exist laws, remedies are lacking. Education through litigation can cause back-lash but is necessary. As there is a lot of courts, especially within the administrative, legal system, there would be a need for a large number of cases to educate them all.

AFTERNOON THEME: LAWYERING AND LITIGATION – HOW TO CHALLENGE THE SYSTEM

Session 3: Implementing Human Rights by using international and national legal standards in strategic litigation. Obstacles to access to justice, cost allocation etc. – and how to overcome them.

Lena Svenaeus, introduction

As Equal Opportunities Ombudsman, I used strategic litigation to challenge unequal pay for work of equal value. This was done, with inspiration from successful litigation in similar cases in Canada, and with cooperation from the Union of healthcare workers. Having allies in the field is important. I actively used EU legislation and brought in experts on this as well as experts on gender stereotypes. Importantly, there was a strategy involving four cases ready to challenge losses. This might be an example of the discussion this morning on the



importance of losing. The cases were based on a comparison between the work of a midwife and the work of a medical technician. The court decided, that the work was of equal value, but viewed the difference in pay as a result of market forces, not gender. The court also decided that the Ombudsman should cover the employer's costs, which were huge. After losing two cases, my successor decided that the risk of losing the remaining two cases was too big and desisted litigating them. I think that is a pity, but it tells us that it is important to make a risk assessment before starting the process.

The legal tools for access to justice are right to a fair trial and right to an effective remedy, which is laid down in the European Convention on Human Rights. There is also useful EU-legislation. Also, what I want to emphasise is the importance of the Paris Principles, which regulated the required competence and responsibilities of national human rights institutions. What is important is that the mandate is clearly outlined in the legislation. This is lacking in Sweden and can explain why complaints are not dealt with in a fair way. The principles also state that a national institution may be authorised to hear complaints on individual situations brought by individuals, their representatives or third parties such as NGOs and other representative organisations.

Furthermore, the principles state how complaints shall be handled: seeking reconciliation, informing the party of their rights, hearing the complaints or transferring to other competent authority, and making recommendations on legal or regulatory reform. A comparison between the situation in Sweden and a class A-institution, the Canadian Human Rights Commission will show the importance this has. The Canadian Human Rights Act states that the commission must investigate all complaints, exceptions are specified. The act also describes the three steps in the investigation procedure. This starts, even before a formal complaint is filed, with an informal contact used to sort out the details of

the complaint. This is quite useful as advice on whether or not the complaint belongs under the commission can be provided, and vital information missing can be added to the formal complaint. This makes the number of cases more manageable and generates better case quality. In step two voluntary mediation is offered, and the investigation process starts only if this does not work.

Recommendations for further actions are provided in the mediation report: dismissal, sending to reconciliation or referral of the complaint to the Canadian Human Rights Tribunal. The commission makes its decision on the basis of the mediation report. However, unless a case is dismissed, it will always be sent to reconciliation before it is referred to the tribunal. Reconciliation is a formal negotiation made after a full investigation of the case is done. Only cases of public interest will be referred to the tribunal. Out of 1488 complaints in 2016, the commission approved 268 and referred another 358 to other avenues of resolution. After an investigation, the commission decided to not go further with 164 of the 268 complaints it approved. It referred 41 complaints to the tribunal.

As a comparison, the Swedish Equality Ombudsman's mandate is very loosely legally defined. The Ombudsman investigated 204 out of 1966 received complaints in 2016. Out of these, ten cases were referred to court, and three resolved through agreements. The Ombudsman also gave a "supervisory decision" on 40 complaints. Supervisory decisions are something invented two years ago, where the Ombudsman herself decides whether the law has been breached. There are no remedies, no sanctions connected to these. It is astonishing that a new appointee as Ombudsman can decide that the way to go is by information and not through negotiation or legal process. This still shocks me, that one person can change the whole process of working with complaints, due to the lack of legislative regulation. Thus, complaints are no longer handled as complaints. Victims are made invisible and without remedies, and information is the strategy of the Ombudsman, not litigation.

From a perspective of sociology of law, I want to emphasise that, when laws are introduced to change discriminatory structures and achieve human rights, effective supervision and effective sanctions are indispensable. You also have to be aware of how bad legislation and bad court decisions petrify discrimination. The issues I think are vital to discuss successful strategies are:

mediation and conciliation as tools for achieving remedies in disputes on disability discrimination; can violations of human rights be eradicated by information about the legislation on discrimination; and what changes in Swedish legislation should be proposed.

Lena Svenaeus is a former Equal Opportunities Ombudsman and researcher in Sociology of Law at Lund University

Kapka Panayotova, presentation of a case against the City of Sofia concerning lack of accessibility of the subway system

The Center for Independent Living, CIL in Sofia have quite a lot of success in litigation for disability rights, depending on how you define success. I have a radical view where success means not just change for the individual but social change from a broader perspective. Bulgaria has a very strong legal framework on accessibility both within legislation for urban development and a chapter within legislation on the integration of disabled people, as well as within the anti-discrimination act. There is also a regulation on specific accessibility requirements. However, enforcement mechanisms are lacking. Accessibility checks are not assigned to special institutions. Those responsible for checking



buildings usually forget to check for accessibility. Existing sanctions are very weak and mostly not applied. Fines are not paid as shown by the information we gathered through the freedom of information act. Out of 15 applied fines during a five-year period, none was collected. The enforcement does not work at all.

The anti-discrimination act is the most important tool for us since it states that impeding access for disabled people is considered direct discrimination. There are two options to approach inaccessibility under the act. You can take the case in front of the Anti-Discrimination Commission, a body where usually at least one person has a disability. The commission rules on whether discrimination has occurred or not, and if it has, it can order the offender to stop or rectify the situation. The petitioner will not receive any compensation. The other option is through the court of justice and a full-fledged trial.

We engage in civic action both by direct protest, different kind of awareness raising actions and by court cases, not just on accessibility issues. The fight against institutionalisation is not successful. Even the famous case of Stanev vs Bulgaria, where the European Court of Human Rights ruled that involuntary institutionalisation is a human rights infringement, has not helped. As Stanev did not receive any support when released from the institution he ended up in the street and died some years later. Now the government is using this as an example of why disabled people need institutions.

We have had a successful case regarding discrimination in education. A coalition of NGOs filed a lawsuit in 2005 against the Ministry of Education claiming that lack of provisions for disabled students in mainstream schools was discrimination. The ministry failed to prove that there are mechanisms and resources to accommodate the needs of disabled students. The case went through all three levels of the court system, and the high court was clear that this was discrimination. In 2010 a regulation on integrated education of children with special needs was passed. Unfortunately, this allowed the parents to choose whether to put their child in a special or mainstream school, resulting in more children going to special schools. Provisions on inclusive education were included in 2017 in the Public Education Act. When asked to refer a successful case of litigation in Bulgaria, I would argue that this is it.

Kapka Panayotova described the case of Vanya vs Sofia Subway and Local Government as less of a success, in spite of a favourable court decision. Vanya claimed damages for costs for taxis of 2.000 euros. The burden of proof under the Bulgarian anti-discrimination act is on the offender, i.e. the Sofia Subway and local government. The court found that discrimination had occurred and awarded Vanya damages of 500 euros. The case was concluded in 2007, but the subway remains inaccessible. So what needs to happen is that more and more people take cases to court, which at some point starts to feel pointless. Unfortunately, I am also sceptic to the use of the CRPD, but hope lawyers elsewhere can convince me of the opposite. There is a multitude of problems: disabled people are not aware or active, and there is a fundamental lack of respect for and adherence to the law.

Kapka Panayotova is a disability activist, researcher, trainer and consultant.

Fredrik Bergman on how to finance and run cases

The organisation I represent, Centre for justice is a private civil society organisation with the aim of defending and advancing individual fundamental rights in court. Our work is based on three pillars: litigation, advocacy and education. Every summer we have a summer camp for law students, and we have had law students doing an internship with us since our start, 15 years ago. The most important part of our organisation is, however, strategic litigation. We represent individuals who have had their fundamental rights violated without charge. Usually, the defendants in our cases are the



government, the state or the municipalities. Our aim, of course, is to vindicate the right of the person violated but also to get landmark ruling by getting cases up to the highest court level. Landmark rulings do not only help the person violated but change the law for many.

At our start, 15 years ago litigation on fundamental rights was non-existing within the Swedish legal system. Even though the European Convention was made into Swedish law 1995 and our court system is pretty decent, there were no cases litigated. Most people, including lawyers, saw the rights in the ECHR as directed towards the government, not as enforceable by individuals suing the government. The reasons for there being no cases are a lack of awareness and funding preventing access to justice. These kinds of litigations demand a lot of resources,

which very few people have. That is why we started the Centre for justice. We raise funding by approaching and convincing private individuals about the value of our work. We need to have a lot of money to cover cases as we potentially have to cover our counterpart's costs if we lose. During our 15 years, we have taken 250 cases to court. We have a high success rate which is worrisome since it means there are many more cases out there not receiving attention. 18 of our cases have been litigated all the way up to the highest court level. All of them with success.

A recent focus has been on the way the Swedish Migration Board interpret and enforce the legal regulations concerning work permits for people from outside the EU area. As they interpret this extremely strict, there have been a large number of cases, where people living and working in Sweden for a long time, are being expelled due to some minor administrative error made by the employer. These people have no right to legal representation. As this gathered attention in the media, we decided to let a couple of law students investigate it. They went through all the cases, and it became clear that this was not just some random cases but a change in the legal approach from the Migration Board. The study also showed that there was no legal ground for this interpretation but the Migration Board choosing to enforce the regulations in an extreme manner. Attention about the situation was lacking, as were resources for the individuals targeted. So, we decided to pick a good case. It is important to find a case which is clear and good enough to hold all the way through the court system.

We found a case of a pizza baker in the north of Sweden. To put pressure on the system, we also used the media: A small video on the facts of the case and why it was legally wrong went viral, but we realised that as long as it was about a little pizza baker in the north, the debate would remain limited. Therefore, we used the fact that one of the groups of migrant workers risking expulsion are IT-specialists. When the public understood that, for example, Spotify risked losing 15 of their expert programmers, the politicians started to act. Our case, in the meantime, reached the highest court level which decided in our favour. The reason the court decided to hear it, was probably partly due to media and political pressure.

Fredrik Bergman is the head of the Swedish public interest law firm Centrum för rättvisa.

From the question time:

The issue of the Swedish Equal Opportunity Ombudsman's supervisory decisions and generally non-functioning was debated. The fact that, it is not just disabled people and organisations that are dissatisfied, but other groups under the Ombudsman's mandate, was used as an argument that

collective pressure might create change. It was also emphasised that it is important not just to complain but to know which kind of change is needed.

Another problem with the Ombudsman's use of supervisory decisions is that, if we do not report to the Ombudsman, the discrimination will not be visible in the statistics, but if we do the lack of enforcement in these decisions risk creating a lack of respect for the laws.

Stellan Gärde was asked to present a case where the right of integrity and protection of your home in the European Convention was used as arguments. The case was about a municipality that, wanted to move an individual from the group home that had lived in for his whole adult life, to another group home. The case was won in the appeal court. A dissenting opinion found that it was against the convention to force him to move, which is interesting since the lower court did not pay any attention to the convention argument. The majority found it unnecessary to try the compatibility of the practise with international law, even though the European Convention on Human Rights has been incorporated into legislation, as the law regulating support to people with certain impairments was found to be sufficient to grant the complainant his rights as he claimed them.

The fact that, Sweden seems to prefer education before litigation, instead of viewing the litigation as part of the educational process, was put forward as a problem. The importance to include the right to oversee and the right to litigate within any national institution was emphasised.

Session 4: Coalition building – how can lawyers, disability rights organisations and universities strategically work together?

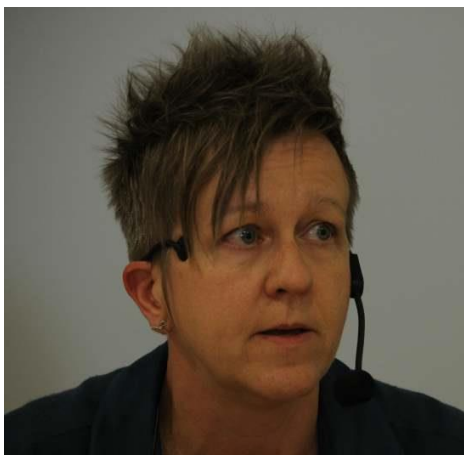
Annika Jyrwall Åkerberg, introduction

Civil Rights Defenders is an organisation working to protect civil and political rights. We do this by using advocacy, strategic litigation and campaigns. Our major challenge is lack of resources, so we have had to find other solutions to strengthen our capacity. We do this through cooperation, with law firms, with universities, and through European networks. We cooperate with law firms that are experts in national law on the subjects of our cases but do not have expertise in human rights. They support us with investigation of the specifics of the national legislation of the subject, and we ensure the human rights perspective. This is a win-win situation. They help us, and we educate them. Another form of cooperation is with law firms that already work with human rights, which do pro bono or low-cost work for us, enabling us to take more cases to court. We also cooperate with universities. We are dependent on interns and use the universities' channels to find these. We always have two interns. We also collaborate through a legal clinic on human rights, where we provide cases that the students investigate for us, for example, the case of the police register on Roma population in the south of Sweden.



Annika Jyrwall Åkerberg is a human rights lawyer, educator and author on rights of persons with Disability. She is also a group leader at Civil Rights Defenders.

Ulrika Westerlund, former president of RFSL:



During my time as president of RFSL we used strategic litigation to protect rights of trans-people in Sweden. I also want to make sure that you never forget the name Kerstin Burman, who is the pro bono lawyer who has done everything for us to achieve human rights. Most rights for trans-people in Sweden have come through litigation, and not through advocacy. In the context of the LGBT-movement this is unusual. The first big win was, the right of adults to freely choose their first name and not be limited by normative ideas of which name belongs to which gender. The case was won at the Supreme Administrative Court in 2009. In 2012, the Administrative Appeals Court in Stockholm decided against forced sterilisation as a

prerequisite to changing the legal gender. This case stopped at the appeals level and did not go all the way up to the Supreme Administrative Court.

Parallel to this, there was political advocacy done. This might be why the decision was not appealed. As the law was not changed until the case had formally gone into effect, mid 2013, unfortunately more people were sterilized during this period due to not being informed about it. During the period 2013 to 2016 we used different strategies to force the government to pay damages to the people being sterilized under the former system. We gathered evidence from people affected. We put forward claims for damages to the Chancellor of Justice, who rejected them. The residing government, in the meantime, had turned down request the for a formal excuse and financial compensation. After the election and change in government, we put forward the request again. At the same time, we were preparing to go to court, using eight cases covering all situations. We were actually standing in the office putting the litigation papers into an envelope when we got the message that the government had agreed to pay damages. We have also litigated cases concerning parental markers.

From the question time:

Nowadays, strategic litigation is part of the way RFSL works. I was not from the beginning.

Ulrika Westerlund is a former president of RFSL and working successfully with strategic litigation for rights of transgender people.

Stellan Gärde, Talerättsfonden:



Talerättsfonden is a recently started litigation fund collecting money to strengthen strategic litigation. They are in the planning stages of their first strategic litigating effort, within the field of education. The Swedish National Agency for Education recommends that municipalities disallow pupils with dyslexia the use of reading aids during the national tests. Talesrättsfonden plans to support cases of discrimination due to lack of reasonable accommodation, against six to seven municipalities that follow these

recommendations. The plan is to bring all the cases to court at the same time and synchronise this with articles in the media. The response from the Agency for Education is, “Good, take it to court”, which we will do. This is done in cooperation with the Dyslexia Association. People from different anti-discrimination bureaus are responsible for the litigations with support from experienced lawyers.

From the question time:

Talerättsfonden does not take cases itself. Its aim is to collect money and fund other agents.

Stellan Gärde is a board member of the Swedish Section of the International Commission of Jurist and initiator of Talesrättsfonden.

Sid Wolinsky on public interest law firms and legal clinics

Let me start by making it clear what Disability Rights Advocates does not do. We do not study anything. We do not do research. We do very little community education. We use the time to sue people. Our focus is strategic litigation on behalf of all people with disabilities, and it is razor sharp. The first thing we do to build coalitions is to work with the legal community. We cooperate with legal clinics, for example, the legal clinic on disability at Yale University. Many of the big private law firms sponsor scholarships for law students to work for two years at a non-profit law firm like ours.

We have also had fellows, from universities like Yale and Harvard, working at DRA. We also had our own fellowship program for some years specifically developed to get young disabled law students to work for DRA. Our primary coalition partners, however, come from the disability community. We try to build coalitions with people who might not consider themselves as disabled, and we try to litigate from a cross-disability perspective. We also try to build coalitions, between offenders and the disability community, by asking the courts to order the defendants in our cases to find a solution to the problem in cooperation with us and the disability community.

From the question time

We have learned during the years that enforcement can take a very long time, up to ten years. We are now in the process of suing the City of New York because the curb-cuts put in 25 years ago are not maintained. Nowadays, we build in long-term monitoring in our cases. Government enforcement cannot be trusted.

Sid Wolinsky is Co-founder of Disability Rights Advocates

From the discussion

The discussion on organisational weaknesses and strengths of the Swedish Equality Ombudsman rose again:

During the discussion on the question whether or not the government can be trusted with enforcement, the problem with the Swedish Equal Opportunity Ombudsman resurfaced. The consequence of a weak, ineffective Ombudsman is that the trust for the institution among disabled people diminishes, so when the Ombudsman wants to litigate there are no reported cases (Ulrika Westerlund).

The anti-discrimination legislation should be amended with a rule that all cases must be investigated with a few exceptions specified in the law. We should make class actions in the area of labour discrimination possible. Also, the Equality Ombudsman should be headed by a board, not by a single

person. This is the organisation of for example national institutions in Canada, Australia (Lena Svenaeus).

We heard several different and differing views on the subject of unions and labour courts:

The trade unions in Sweden can have a real impact when they take on cases concerning discrimination within the labour market, as they have representatives on local, regional as well as national level. They handle a very large number of cases and have the capacity to do so (Stellan Gärde).

The Swedish Labour Court is "a horror" on cases of ethnic discrimination. First of all, it is a parts-based court, and it is doubtful whether you can trust employers and unions to prioritise discrimination cases. The real problem, however, is the three judges that are supposed to be impartial as they do not understand ethnic discrimination at all or any other discrimination for that matter. If we are going to keep the Labour Court there is a need for a lot of education (Lena Svenaeus).

The Norwegian Labour Court and unions are "a horror" when it comes to disability discrimination. The only institution understanding disability discrimination in Norway is the Tribunal (Berit Vegheim).

We can learn how to organise on the local level from the unions. Sometimes the major changes come from litigation on the local level (Sid Wolinsky).

Summary and reflections by Susanne Berg

I am not going to summarise individual people. This is more my thoughts and reflections which I have had for a long time, and which tend to develop every time I am in a meeting like this. They are about the law as a tool, my situation as a disabled person, the fact that I belong to a disability movement, and centres of power in society. This conference is about using the law as tool, and it is also an Independent Living conference.

For me Independent Living is more than a philosophy. It is not something you teach. It is not something that is provided to you. It is something you do, something you do by living. It is more about how you do things, than what you actually do. Independent Living is also about learning by doing. It is about learning by doing together with other disabled people and allies. At the same time the Independent Living movement is built on principles, which we all adhere to in our own individual ways. It is also an extremely pragmatic movement. We do not really care what tools we use as long as they get us to where we need to be. Law as a tool is extremely good for people like me, who like Independent Living. It is a tool and a tool is what you make it. Well the tool is not really one tool. It is more of a toolbox.

For me, today has been a tale of intersections. One of them has been the intersection between lawyers and disability NGOs. We heard people talking about not taking on cases unless in cooperation with a disability organisation. And I like that – a lot. I also heard that it is important that, when lawyers work together with disability organisations or for disabled individuals, it is not because they should help us. It is because they should learn.

We should be fearless. We should all learn by doing together. And when we do this together we should remember that it is not primarily about winning cases. It less about winning legal cases than it



is about righting social wrongs. We should all learn by doing together and follow the cases from their start to their conclusions, which are not necessarily the same as a decision in court. This brings me to the next intersection. The intersection between using the law as tool and using other kinds of tools, like political advocacy, media etc.

There has been a lot of talk about such other tools today, which might be because we are in a Nordic setting here. The Nordic countries tend to talk about welfare rights and how to educate people. If we could just teach the people in power to understand. Things would be so much better. This is not really something I like to prioritise. Instead, we could use both litigation and use CRPD to appeal through the administrative court system. We could use all the laws and all the court systems, and we could win also by losing. Litigation can be a trigger to enact social change. I think we need to focus on this because we cannot as individuals sue the same company over and over and over again each time there is a new leaflet or a new door. At least the discrimination law should be seen as a trigger, a flamethrower or cattle prod, used to make the mainstream system work better. Then there is the intersection between disability and other grounds for discrimination, and between disability law and other legal areas. How we can learn from other fields of discrimination and people within the other discriminated groups. These are some things I have heard today.

If we want to use the law as a tool. If we want to make ourselves powerful by using this tool. If we want to make ourselves powerful not just through winning cases but righting social wrongs, the first intersection must be strong. It is the intersection between the disability community and the law, and maybe also the lawyers as tools for social change. It is important that we do not just empower individual lawyers, whether they are disabled or not. We need to empower all disabled people. We need to use the law as a pedagogical tool, not view it as compensation to a discriminated individual. In the US you can claim remedies that actually remedy the situation. We do not have that in Sweden. In Sweden, we have money. So here, we have to use a method of “shilling or shame”, pay and pay again, or shame people. You can shame people even if you lose a case. We need to be more fearless. We need to take on cases more towards the edge. For me, it is important that we lose, but in a classy, smart way so the argument can live on and be used somewhere else. Good legal arguments educate lawyers and courts.

If the law is a tool, it will be as strong as we make it!

