

Conference celebrating ENIL's 30. Anniversary, Brussels 2019

Keynote: "Reflections on the past 30 years"
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Thirty years ago, in April 1989, at the European Parliament in Strasbourg, ENIL was founded. 72 persons with disabilities from some 20 countries had come to the first European conference on personal assistance and Independent Living. Most of the participants I knew personally. In my keynote, I suggested building a flexible, flat network of grass root organizations for working for independent living and personal assistance. The suggestion was adopted and I was elected chairperson of the new organization.

I am humbled and grateful for still being around and being able to be here today. I am warmed by being with friends. I am proud that ENIL has done well and is thriving. I am glad to see many young faces here who promise to continue the work of our generation. I miss close friends who have left us, among them Bente Skansgård from Norway, Jan-Jan Sabbe from Belgium, Kalle Könkkölä from Finland.

What have we achieved in the last 30 years?

We built a lobby organization through which we have access to Members of the European Parliament and the Commission. We have our people on the board of other lobby organizations such as the European Disability Forum. We have become a voice in Europe with over 80 full- or associated member organizations. With support from the European Commission, sometimes, we have been able to conduct research, organize events and campaigns, carry out projects, gather statistics and formulate arguments in working for our goals. At the initiative of our Irish friend, the late Martin Naughton, we have been demonstrating for our rights and informing MEPs about our requirements every second year at the European Parliament. Our member organizations have developed projects and activities that have become showcases and best practices, particularly in the area of personal assistance and de-institutionalization. An increasing number of organizations are run by disabled people in management and board positions - not only among the ENIL member organizations but, to some extent, also among medically oriented organizations. This development demonstrates to people with disabilities, to governments and the general public that persons with disabilities are capable and effective citizens who can work for the best interests of their group.

As a world-wide movement, we have been tremendously successful in influencing language and content of the United Nations Convention on the Rights of Persons with Disabilities. We can be proud about our people who served on the CRPD Committee such as Prof. Theresia Degener, and about the cornerstone of the Convention, Article 19 that, in its very name, mentions our movement and its demands. We can be proud about the CRPD Committee's General Comment No 5 on Article 19 that defines Independent Living and what constitutes an institution. These definitions, hopefully, will be used in court someday.

In 1989, as a group, disabled people were second class citizens. In 2019, we are still second class citizens. According to government statistics, we are still worse off than the majority population in terms of education, employment, income, social relationships, family formation, in prominent positions in culture, science, business and politics. Whenever the economy slows down, we are the first to feel the consequences in the form of reduced services and payments. But even in a blooming economy, we experience budget cuts when our governments feel the need to help the rich get richer. Let's face it, the general public and the

politicians still don't see us as ordinary human beings and citizens who deserve the same opportunities as everybody else.

To liberate our brothers and sisters from institutions has been one of our main goals. But institutionalization in Europe has actually been rising in absolute terms – often financed by the European Union Structural Funds with money that could be invested in Personal Assistance. While our brothers and sisters in the US will soon celebrate the 30th anniversary of the Americans with Disabilities Act, we still have not succeeded in putting European Union legislation in place for removing physical barriers in the built environment.

I could go on enumerating all the areas of private and public life from which most of us are marginalized or excluded by over-protection, paternalism, attitudinal and physical barriers, by outright prejudice and discrimination. But we must not see ourselves as helpless victims. As victims, as passive objects, there is little we can do to change our situation to the better.

Here, we can learn from other oppressed minorities that have shaken of the victims' role and fight for equal rights and opportunities, such as racial and ethnic minorities, the women's or the LGBTQ movement. For one, their organizations help their members see and understand the causes and mechanisms of discrimination including the internalized oppression which many of us turn against themselves. How can we expect other people to see us as human beings of equal value when we ourselves, deep down, are not convinced that we have the same obligations and rights as our non-disabled brothers and sisters, friends and neighbors? In self-help groups, we can help each other on the way to proud citizens with disabilities who demand their rightful place in family and society.

Other minorities work also through the arts, literature, film. They fight their way into business, science and politics. And, they use the law as a tool for social change. In every country, in the European Union, the Council of Europe there are laws, directives, international conventions that can be used in court for implementing our human and civil rights. If you want to learn more about disability rights and laws and how to use them in fighting discrimination, you are welcome to join our FaceBook group with the name "Disability Rights Defenders".

I pointed out several areas where ENIL can advance our positions in society. Much of that work must take place at the grass-roots level. Let us revive the idea of ENIL as a flat network where individuals and member organizations can share and learn together how to overcome internal and external oppression, design services that make us more independent, and advocate for our rights. We need to do this work ourselves. We are the best experts on our needs. We need to be in charge of that work. Now and in the future.

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