



International Conference: Independent Living through Direct Payments

Expertise Centre Independent Living

European Network on Independent Living

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What is the European Network on Independent Living ENIL by Jamie Bolling

Hello everybody, my name is Jamie Bolling. It's a pleasure to see so many countries represented here today. It's a necessity for ENIL as an organization! We need as much representation from as many countries as possible! I'm looking forward to meeting all of those I don't know and I'm happy to see all of those that I do know. When Viviane challenges us to think of the kind of goal we should have for the Independent Living Movement and with our research, I say that we need a national centre of Independent Living in each country. That we need to have disability studies with people with disabilities involved at all levels in our research. And we need to have an Independent Living directive at EU level, for personal assistance in all European countries. Now to my prepared speech - What is ENIL? My speech is divided into three parts. I have 20 minutes and will try to keep the time!

What is ENIL? What are our challenges and our hopes and how can we cooperate?

Who am I? I have three passports, two kids and one passionate drive. I was born in the USA and I lived 16 years in Geneva, Switzerland, so I'm French-speaking as well. I have one passionate drive for human rights against discrimination. That came after my accident and my experience of being dependent on a wheelchair for mobility. In 1991 I fell off a horse. Before that I was a white, American wife with a middle working class background. I had not experienced discrimination during my time



when in Europe. Maybe if I had been a black American, but not as a white American. It wasn't until I ended up as a wheelchair user and found I couldn't ride the bus, go to the neighborhood store or to the cinema. That I did not receive the support I needed and so on that I felt discriminated. I don't have to tell you about the situations, you all know what I'm talking about!

About my job: I have been working in the Independent Living Movement since 1993. I was the president of STIL - Stockholm Cooperative Independent Living back in the 90s. I have also worked with international development cooperation and partnerships between different countries and Sweden. Today I'm working as the executive director for ENIL as of May last year. This is a challenging and a very exciting and interesting job.

I guess all of us know ENIL, certainly those who are members, and for the rest of us, I hope you'll become members too! ENIL is a drive for the future: what we can do together for civil society. When I came to Sweden, it was exciting to find so many NGO's and people working for different things. We can take this week with the ship to Gaza, the drive and the cooperation and see what we can achieve together! I was the vice-president of the United Nations Association as well as working in the Independent Living Movement. I see that we can have allies with a lot of different organizations and we need to develop them. With allies we can become stronger. I tried politics thinking "gosh, we don't get anywhere, there is nothing happening". But as a politician I think not much happens either. I am still active though with the Green Party in Sweden, we can never give up!

The European Network on Independent Living is a European wide network of disabled people. It started with 80 people meeting in 1989 in Strasbourg for a PA conference. Now we have members in quite a few countries. But we don't have activity in all EU countries that I know about for example in Poland and we don't have a partnership member organization. So if anyone is here from Poland, we need to talk to you. We have certain countries that are more active than others, and if you need support, that's what ENIL is for. ENIL supports member organizations, so that we can grow together. ENIL is a forum for Independent Living organizations or CIL's at local, regional, national and international levels. We need a national CIL in each country, but even the local level is important. It's important that we are working at all levels, so that we become a much stronger movement than what we are today. And we need also our non-disabled allies. If we are going to get a directive at the European level, we need to be more than just we who have disabilities. We need all of our friends, families and our allies in different organizations to support our demands. What is unique about ENIL? ENIL is a crossed disability organization. It's not only for people in wheelchairs, the blind or the deaf. Sometimes there is a type of competition between different impairments. We are an organization for all people with disability working for human rights. That's what is important: the right to full participation in society no matter what disability we have.

I don't know how many of you were at the Freedom Drive last year? Some I know. We had the twentieth anniversary of ENIL, last year 2009. We celebrated at the Freedom Drive. Back in 1989, which was before my career in the Disability Movement, 80 persons from 20 countries met in Strasbourg. I know that Bente Skansgård who is here with us today, was there in 1989. There were probably others of you as well? These people got together to talk about personal assistance and the need for personal assistance. This was one of the most important meetings to start driving for personal assistance here in Europe. When we had the Freedom Drive last year, we had also a



conference on personal assistance, as it is one of ENIL's main issues. Today we are discussing direct payments, which is also about personal assistance and services.

ENIL has members from 20 countries. Today we have organizations from Finland down to Spain. Iceland joined us last year, so from Iceland to Bulgaria. One of our major activities is our biannual Freedom Drive, 2009 was the third one I think. Every other year since 6 years, there has been a Freedom Drive for inspiration and engagement of we in ENIL.

When we had the Freedom Drive last year, we handed over ENIL's 8 demands which we want to obtain, to the president of the parliament, Jerzy Buzek. What are we working for in our movement? One issue is that independent living should be central in all policies in the European Union. Another is that there should be a development of community-based services to achieve deinstitutionalization. There are many people still in the institutions. Not only in Eastern Europe, but also here in the west, in France, Germany and different other countries. In Sweden we closed institutions, I'm not sure how many years ago, but they are trying to sort of open up them again. Some people live in places that they don't really have a say on how they want to live and what they want to do according to the UN convention article 19. So we have to fight against institutionalization, and for the implementation of our human rights to personal assistance according to the United Nations convention article 19 on independent living, and the right of freedom of movement. There is an example of a person offered a job at EDF (European Disability Forum), but they couldn't take the job because they couldn't take personal assistance with them from Finland to Belgium. If we obtain personal assistance, we can still only live where we live right now, we cannot move to another country. Another demand is for 5% of EU development funding going to independent living programs in developing countries. Number 6 is the ratification of the European Convention. When we had the Freedom Drive last year, we had two people from the disability unit of the commission talking to us. At that time there were about 17 countries having ratified the convention. I just read that Slovakia ratified on May 26th. That is just a few days ago, so I'm not sure how many countries have ratified as of now. Our goal is for all EU countries having ratified the convention, because only then will the EU do it and not before. Number 7 was about the disability specific directive. At the board meeting last week we called it the independent living directive. We need an IL directive at the European level. Number 8 is to see that we disabled and our organizations are involved at all levels of policymaking. In research that we talk about today, there should be nothing about us without us. On this power point picture, you see Bente handing over the demands to Jerzy Buzek at the Freedom Drive last year in September.

Now I will describe the governance structure of ENIL. How does ENIL work? At the top it starts with our members. ENIL is as any organization only as strong as its members. The members then elect the board. This September there will be the general assembly of ENIL. I hope that as many as possible will come, so that we have a good democratic election of the board. Will the old board continues or will we have new board members coming in? The board when elected then decides how they want to work. Right now, we work through an executive team, with the executive director myself, which I share with Martin Naughton as the co-director. We are complementary and working together with the board in our decisions. We have a secretariat in Valencia. We have had financial funding from the Valencia government since 2006. They support ENIL both as the headquarters for Europe and for the development of independent living in Valencia and in Spain. ENIL has 3 programs. We have Valencia and then the Progress program, which is ending this year. We had Progress money for 3 years or funding from the Commission. We have just sent in a new application and we will see if they accept



us for another 3 years. Then we have what is called the ECCL (European Coalition for Community Living). This is the program where we work against institutionalization. And then we are back to our members. Our members are working with us as partners where we are trying to grow with stronger national CIL's. Member organizations are working in different areas. We always try to keep good contact with the grassroots and our allies at all different levels.

From this year, we have four regional teams. We have the secretariat in Spain responsible for southern Europe. We have YHD in Slovenia as the eastern European office. JAG in Sweden also an independent living organization is the northern office for ENIL. ENIL Dublin is the organization for western Europe.

Northern Europe (where I am living today, I am living in Sweden) is comprised of Denmark, Sweden, Norway and Finland and also Iceland that has joined us recently. Then we have the three Baltic countries that are part of our northern Europe region, with Lithuania, Latvia and Estonia. We are going to have a meeting for the northern block in August. We will have there a two day conference like this conference, where we would like to strengthen the northern independent living movement. So we are hoping to have representation from all countries. The goal is to have a meeting in every region. So watch on the website www.enil.eu for the different activities that are happening.

Progress is a European program for employment and social solidarity. This is a program working for uniformity in EU laws, employment, social inclusion, protection working conditions, non-discrimination, gender equality etc. All of these are important when disability issues are concerned.

In Valencia, as I have already told you, the office is promoting independent living in Spain and southern Europe. And it is the headquarters for ENIL.

ECCL is a European wide initiative working against institutionalization. It started actually in 2005, by Autism Europe, the centre for policy studies at the Central European University, EDF (European Disability Forum) and ENIL, as well as Mental Health Europe and Open Society Mental Health Initiative. Recently there was a conference and report given out about how structural funds are used. They are to be used to tear down institutions, and not to build them up, but this is not the case. The report is on our website and also on ECCL's website.

So what are our challenges?

The financial crisis is contributing to the decrease in our services. Many countries are using the financial crisis as an example for cutbacks.

The lack of empowerment is another challenge. Many people within the movement don't have strong self-confidence and don't have strong self-esteem. We need to build up one another through peer support, so that we are all strong and can work together.

The need of personal assistance is another challenge. I was lucky to fall off a horse in Sweden. Without insurance in the United States, I probably wouldn't be sitting here today. But I was in a country where I had access to support, to the university, to different things, to be able to become a strong activist within the movement.



Disability research poses a challenge. There are too many experts who aren't working in partnership with the disability movement when doing research. They research about us without us! We have the expertise, so it is important to have cooperation between the two of us.

Our hopes? We need a wider and stronger organization, a strong CIL at all the different levels in all countries. We need empowerment of our individual members and of our organizations. And we need representation of disabled people at all levels. Yesterday for example, I got an e-mail concerning the AER (Association of European Regions). They are going to do a project on the UN convention. I'm wondering how many of us are sitting in any of the regions around Europe? We need to try to make sure that this project and other projects include us and don't just talk about us. So again: nothing about us without us!

How can we cooperate? We can cooperate through membership. If everybody here becomes a member of ENIL and gets other people to join our organization! Get your friends, your families and all of our allies to become members to strengthen our CIL's at different levels. Gaining allies and the success of the 8 demands that we gave to the president of the EU parliament last year should be a focus of our cooperation. There are various activities through Progress in which we can cooperate. National marches, round tables on the disability pact, the disability watch dog, read the ENIL newsletter and the ENIL website to stay up to date!

See you in the movement! Thank you.

