

ENIL's Presentation to the European Parliament MEP Disability Intergroup

7th September 2005

Introduction

Firstly I would like to say how delighted and honoured we are to make this presentation to the distinguished members of the Disability Intergroup. We know you have been doing extremely valuable work on behalf of the rights for disabled people in Europe in many different ways. We appreciate that you found time to be able to listen to us today. We value the opportunity very much in being able to discuss with you the very important subject of Independent Living and Personal Assistance services.

Why have we come to the European Parliament and Why are we addressing you here today?

We have come as part of our Strassbourg Freedom Drive campaign on behalf of the European Network of Independent Living (ENIL). ENIL strives to promote and campaign for the development of Independent Living throughout Europe. We are a Human Rights grass roots organisation who is very much in touch with the needs and wishes of disabled people. We feel now, that in 2005 and with this new European Parliament it is the ideal opportunity that the rights of disabled people should be raised higher on the political agenda together with the importance of Independent Living.

We have come for a number of reasons, in particular to inform you more about the situation of disabled people in different European countries. We want disabled people throughout Europe to have the same equal opportunities, to be able to live an independent live in all Europe, not only in the Scandinavian and in other European countries.

Our main aims and objectives of this Strassbourg Freedom Drive are:

1. Raise the awareness of Independent Living on a European level

2. The portability of Personal Assistance Services from country to country in order to enable disabled people to move, live and work from EU member state to another
3. To emphasize the importance of Independent Living as a community living alternative to institutional care
4. To highlight the need for a right to Independent Living
5. Aid for disabled people in developing countries

Raise the awareness of Independent Living on a European level

We want to overcome the situation where Independent Living is available to disabled people in some countries like the UK, Sweden, Denmark and Finland and others, whereas disabled people in countries like Estonia, Hungary, Greece and Portugal do not have such personal assistance schemes available. We ask you to support us in this demand and build upon the good work of the Madrid Declaration (2002) and the Tenerife Declaration (2003).

The portability of Personal Assistance Services from country to country to enable disabled people to move, live and work from EU member state to another

We would like to see every country throughout Europe have Personal Assistance schemes to help disabled people to live independently. When we talk about personal assistance schemes we mean the support disabled people need on a day to day basis in order to do what they want.

We want to see disabled people to be able to have freedom of movement like all other European citizens. ENIL has felt strongly about this for many years. We were very encouraged by the moves to revise European Social Security regulations in order to allow disability benefits to be exported. Disabled people have faced very many problems in this area and we continue to be concerned that there are restrictions on our free movement particularly in respect of the lack of personal assistance provisions in different countries and the inability of disabled people to have financial support to travel with their Pas.

To emphasize the importance of Independent Living as a community living alternative to institutional care

At a time when the European Commission is seriously looking at the situation of institutional living for disabled people throughout Europe in their attempt to come up with alternatives, we feel it opens the door to Independent Living. We feel that Independent Living has always been a very good practice of alternative community living and needs to be built upon. Now is the time to ensure that all those disabled people in institutions who have lost their freedom to be changed and be fully included in society and not excluded.

We are fully supportive of the work of the Disability Intergroup to encourage financial support by the 7th Framework Programme on Research to investigate the quality of life and living situations of disabled people, in particular the status of disabled people living in institutions. Once this information is fully compiled the EU will realise the appalling situation that exists and will do something about it.

To highlight the need for a Right to Independent Living

We feel it is important to have equality for Independent Living as a Right. We do not want disabled people incarcerated in institutions, unable to make basic decisions about their life, when to get up and when to go to bed, what to eat, how to spend their day, unable to go to the local community when they want and many more. We believe these are infringements on their lives and violations on their human rights.

Aid for Disabled People in developing Countries

We feel that it is important that the European Union takes a lead in developing community projects for disabled people in developing countries. This is because disabled people in these countries experience extreme hardship and poverty and lack of basic fundamental services due to the economic conditions of their countries. A number of Scandinavian countries have already developed some very good models of practise in this field that can be built upon.

For instance the Scandinavian Governments have just adopted a joint communiqué with the Nordic disability organisations on disability and development and are to launch a joint action plan on mainstreaming disability in development cooperation policies and programmes.

In two weeks there will be a major conference in Ethiopia on 23-24 September on the African Decade of Disabled People to bring together disability organisations from all over Africa as well as other parts of the world including Europe with key decision makers to put concerns of disabled people to the top agenda of both African and donor Governments. The European Parliament could certainly assist in promoting the African decade campaign.

Independent Living in different European Countries

What is the situation throughout Europe and why is it so different in countries like Sweden, Norway, Finland and Germany? It is impossible to give a comprehensive overview of Independent Living in all the European countries so all we can do is to highlight some key examples.

Cooperative Model of Independent Living

The cooperative model of Independent Living works in the way that disabled people set up their organisations and cooperatives which then organize and manage their Personal Assistance schemes. This means the control is in the hands of disabled people's organisations, and this usually works best, because disabled people originally started these schemes, and they know how they work. In Norway and Sweden, this particular model works well, but throughout Germany it varies. There are often many regional differences where these kinds of cooperatives are set up and in other places they simply do not exist. This is usually because in these areas there are no active disabled people's organisations. The cooperative model helps the individual to manage their Independent Living schemes.

Direct Payments or Personal Budget Schemes

In the UK, Holland, Belgium and Austria there are schemes that are known as Direct Payments or Personal Budgets schemes. This means that the disabled people receive their money from the local authority according to their needs. It is then up to the individual as to whether they manage the scheme entirely themselves or find some peer advocacy support to help them run their scheme. The Direct Payment schemes has worked extremely well in the UK for some time now for many disabled people of all impairments benefiting from it. This includes people with learning disabilities, mental health service users and older people.

Other Countries

It is surprising that even in developed countries like France there are no real personal assistance schemes. French disabled people have to make the best of the minimum of benefits they receive to cover the support to live independently. Our French disabled colleagues hope that recent changes in disability legislation will help to improve the situation. This means that many disabled people in France live in a shoe-string unable to get as much support as they need. However, they are not alone as this is the situation in many other European countries.

Italy has developed some schemes in Florence, Venice, Torino, Rome and some other places. However, there are still huge regional differences in terms of what is available to support disabled people to live independently. So there is still a long way to go to fully meet the needs of disabled people to achieve Independent Living. Florence has regional legislation for Personal Assistance which has helped to make a difference. Specific legislation in a number of other countries has helped to improve the situation like in the UK, Sweden and Norway.

In Spain over the last few years the Independent Living movement has worked very hard to get Independent Living and Personal Assistance schemes going. Now we see the beginnings of pilot projects in a number of Spanish cities like Barcelona, Valencia, Madrid, Vigo and others. This is a beginning but there is still much to be done to develop this further. This did not come easy as the Spanish disabled people had to work hard to achieve this. This

development is most encouraging as there has been for some time now a divide between Northern and Southern European countries in terms of Independent Living initiatives.

Sadly the picture is very different in Eastern Europe. There are a few disabled people able to live independently, often with little support. Slovenia is probably ahead of the bunch. Other attempts are being made in Slovakia, the Czech Republic and Latvia.

This is one of the reasons why we have come to the European Parliament, in order to raise the political profile for the Independent Living opportunities for our brothers and sisters in the Eastern European countries. It is a shame that we do not have more representatives of disabled people from these and other countries today. One of the main reasons for this lack of representation is because these disabled people did not acquire the financial sponsorship or support to help them get here.

Conclusion

As you know, the European Commission has instigated a number of pilot projects looking at institutionalisation. This is an ideal opportunity to encourage EU member states to develop more community based projects which can enhance disabled people's lives and improve their opportunities. We are therefore pleased that the European Commission has decided to choose community living for its major conference for the European day of People with Disabilities this year. We only regret that they did not approach us in their planning, being as we are, the experts in Independent Living and community living options.

We know many of you here today have met disabled people in your countries informing you about the situation. We appeal to you to support our cause to enable disabled people to live their lives as they want, and with the future which will be free from the spectre and fear of ending one's life in an institution. I am sure many of you here are aware that considerable work has been done over the last few years, particularly around drawing up an UN Convention "Protecting the Rights of Disabled People". We know this is in the right direction, but wouldn't it be marvellous if Europe set the president in both

establishing Independent Living as a right and develop the long term policy phasing out institutional living in Europe in order to eradicate the violations of disabled people's human rights in institutions.

For those of us who have been fortunate in achieving Independent Living it has changed our lives. It has transformed disabled people from being passive recipients of services to active disabled citizens of our communities. This is not only positive and healthy but makes good social and economic sense for the future of Europe. We plead to you today to support our course and we thank you for listening and engaging in this session.

**John Evans OBE
President of ENIL
September 2005**