



European Network on  
Independent Living

<http://www.enil.eu.com>



## **ENIL's Submission of our "Eight Key Demands" to the MEP Disability Inter Group at the European Parliament. 24<sup>th</sup> September 2003**

### **Introduction**

Firstly on behalf of ENIL can I thank you for finding time to arrange this meeting in order that we can make our presentation. We value the opportunity very much in being able to discuss with you the very important subject of Independent Living and Personal Assistance services, and in particular the 8 key demands we have formulated for this occasion.

As the representative European organisation of disabled people, who need Independent Living and Personal Assistance, we felt it was important to bring these issues to the European Parliament. We are a Human Rights grass-roots organisation, who are very much in touch with the needs and wishes of disabled people, and feel that these "8 key demands" are very much current in the wishes of disabled people.

### **Eight Key Demands**

#### **A European Wide Policy on Personal Assistance**

We believe that the availability of Personal Assistance Services is long over due as there are still many countries within the European

Union, who still do not have established and effective personal assistance services for their disabled people. We felt this issue to be very pertinent this year as it is the European Year for Disabled People. It became one of ENIL's aims of the year to try and publicise and implement this more.

As personal assistance services are essential in enabling disabled people to live independently we felt this was following on from the calls for Independent Living in both the Madrid and the Tenerife Declarations. We feel it is important now to build upon this recognition as both of these declarations came out within fourteen months of each other and this is why we want to bring these to the attention of the European Parliament. We also think that our "8 key demands" fit well in to the above declarations.

### **Institutionalisation**

We believe that self determination and independent living should be a basic right for disabled people who aspire to it. The opportunities to live independently provide a sane alternative to institutionalisation which is both healthy to the individual and economic for the State. As institutionalisation is part of the current frame work of the social exclusion policies of the EU, it makes common sense for the EU to support Independent Living in community services as a viable alternative to disabled people living in institutions.

As long as Institutions exist, the spectre of a disabled person finally ending up in one is a fear that haunts most disabled people through out their lives. Institutional life denies a person, real citizenship and participation in the community. It also takes away ones freedom. For those disabled people who have already experienced institutional living and have tasted that reality and the loss of control over the basic decisions of their life, know only too well, that it is a large price to pay, sacrificing ones own contribution and livelihood in the community.

As I speak I shiver at the thought that right now at this moment in time there are thousands of disabled people in institutions in every EU Member State. I dread to think of what the exact numbers of disabled people are in institutions throughout Europe. It touches me

deeply especially as I have personally experienced some years in an institution myself. I was one of the lucky ones who originally pioneered Independently Living in the UK as a solution, in order that we could get out and escape from the imprisonment of institutional living.

For a disabled person living in an institution these are just a few of the sacrifices that one makes in terms of losing ones basic Rights:

- Are denied their rights by having to live in institutions
- Do not have the right over decisions that affect their lives
- Are often denied choice and control over their lives
- Do not have the right over who gets them up and puts them to bed
- Do not have the right when they can get up and go to bed
- Do not have the right to chose their own personal assistance
- Do not have the right to basic services
- Do not have the right to decent housing
- Do not have the right as to when and what they can eat
- Do not have control over their own money – as many institutions withhold their pocket money and benefits which they receive from the state

This paints a bleak and gloomy picture, which makes one realise why disabled people are fearful over the spectre of ending up in an institution. This is without even touching on the bad conditions they live under and the potential physical and sexual abuse and victimisation they experience.

## **Representation of Disabled People in European Social Inclusion Strategies**

The answer to this is social, economic and political. This is because of the lack of implementing good social policy practice excludes disabled people. This is ironic especially when we live in a time when the directives from the European Union and National Governments are towards social inclusion. This is meant to include disabled people in all aspects of life, social, political and economic, yet what happens sometimes is the opposite. Disabled people find themselves victims of a system that disenfranchises them and keeps them at the poverty

level, dependent on benefits, lacking opportunities in employment and training, and further isolated in their own communities because of inaccessible public transport systems.

From a social perspective much of it stems from bad social policy planning, but the root cause is through fear, ignorance and a poor attitude to including disabled people in the main stream of life. There is a lack of commitment both by the EU and national and local Governments to address this problem. This is clearly indicated in many instances where disabled people and their representative organisation's are excluded from any real involvement in planning teams in developing appropriate services. There is still a problem fully understanding what real consultation and user participation is all about. They neglect it at their peril, but unfortunately it is disabled people who are the real victims in the end by not getting the services they require. There should be a continuation from beginning to end in the planning and delivery of proper, appropriate services. This should work from the top down, from national government policy and legislative level to the regional and local government levels. In this process there should be forums, networks, planning and consultation groups, that constructively involve disabled people as real participants, planners and experts in their own affairs.

### **The Right to gain Personal Assistance Services regardless of Impairment, Ethnicity or Age**

In order to avoid social exclusion to different impairment groups in the provision of personal assistance services it is essential that this is planned and delivered equitably right across the board. This should also include ethnicity and age.

### **Promotion of the Appropriate Implementation of the Philosophy of Independent Living**

Independent Living has been a catalyst for the Disability Movement in the struggle for our Civil and Human Rights. It has provided us with a framework with which we can both challenge and monitor the structures of society. Independent Living touches upon the nerve fibres of everything we do in our every day lives. This is why it is so important in highlighting our needs and aspirations, and at the same

time it significantly provides us with a direction to progress our overall movement.

Independent Living has provided us with many answers and solutions to the problems and discrimination we face. It has become our blue print for survival and liberation. Through the philosophy and practice of Independent Living, disabled people have been able to regain more control and power over their lives. We have been able to organise and develop our own organisations, and at the same time operate more control and choice over our life styles by setting up our own Independent Living, Direct Payments or Personal Assistants Schemes. It has helped to politicise many disabled people. We encourage the EU to support the implementation of the Independent Living philosophy.

### **Overseas Development Aid for Disabled People**

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 the lack of basic fundamental services due to the economic conditions of their countries.

A number of Scandinavian countries and some international disability organisations have already some very good models of practise in this field that can be built upon.

### **Disabled People's Human Rights Violations**

We think that as disabled people's human rights are still being violated in many European countries it is very important that the legal instruments of antidiscrimination legislation are strengthened. The non-discrimination clause in the Amsterdam Treaty is a step in the right direction but we need much stronger enforceable legislation in order to protect the rights of disabled people in the EU.

### **The Right to retain Personal Assistance funding when Moving around EU Member States**

For some time now ENIL has felt strongly about this, especially as it restricts the freedom of movement of disabled people, unlike other non disabled citizens of Europe. We were encouraged at the recent advance at the European Parliament of the progress of the new social security regulation allowing that benefits could become exportable throughout the EU for disabled citizens.

## **In Conclusion**

So we come to the European Parliament to meet our MEP's and yourselves of the Disability Inter-Group, in order to try to encourage the EU to promote and develop new policies and strategies which can include our "key demands" , particularly Personal Assistance services at a European level. We feel now is the right time to encourage this debate at the European Parliament. This has been one of the goals of the year for ENIL.

We feel that it is unfair and unjust that some EU countries provide Personal Assistance services for their disabled citizens and others do not. It is only equitable and within the concept of harmonisation to make this available throughout the entire EU.

We hope that bringing the issues of these "key demands" to you today can open up a positive dialogue between us, to try and bring this change about. We therefore welcome the opportunity in seeking your expertise and knowledge of the EU institutions to help this process. We hope it will be possible to formulate a Resolution on our "8 key demands", which can go to the European Parliament.

May we end our presentation to you by thanking you for listening and look forward to trying to answer the questions you may have in order to explore the possibilities.

John Evans.  
ENIL President  
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