

Speech on disability policy in EU Parliament

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I want to thank the Disability Intergroup and the EU Belgian Presidency for this meeting and the opportunity to make a statement.

I am Peter Lambreghts and I work as a researcher and policy staff worker for the Expertise Centre Independent Living, located in Ghent here in Belgium. I am also a board member for ENIL, the European Network on Independent Living, a grassroots organization with members from all over Europe.

What we see happening throughout Europe is an increasing amount of persons with a disability who want to take full control over their lives and their support. We want self-determination, freedom of choice and participation as a full citizen in our society. This is in accordance with the contemporary view on disability, which is reflected e.g. in the UN-convention.

It is clear that we find ourselves in an ongoing paradigm change. There is a growing awareness that we must leave the medical model which pushes people with a disability into a passive and dependent situation. But in reality, most of our national legislations, structures and services for the disabled are still based on this medical model. This is a huge obstacle for the emancipation of people with a disability. Most European national governments say they want inclusion and participation of people with a disability. However, they do not adapt their legislations and their structures to make this happen. Often they ratified the UN-convention, but keep on spending the available budgets on building and subsidizing institutes. Also personal assistance, which is a key element for Independent Living, is rarely a real and accessible right but rather a favour for a small number or even non-existing.

Euro-sceptics will say that I am in the wrong place here to make this statement. They will say the EU is all about economics, trade and finances. When it comes to social and human rights issues, the EU is synonymous to hollow words and immobility. On the other hand, there are positive or over-optimistic views. Some believe the complete European ratification and implementation of the UN-Convention will happen quickly. They assume we will have a binding EU-directive on Independent Living through Personal Assistance. This directive will empower and emancipate all disabled Europeans in the near future. Only the future will tell us which view is right.

But I do believe my presence and words today are neither a waste of time nor a waste of energy. I think this meeting will recognize my expertise that I have build up through professional experience, through my national and international network and through my experience of living with a disability. This expertise, and maybe the fact that I am a Belgian resident, brings me to highlight two crucial issues for the Belgian EU-presidency. These issues should be an important part of the priorities of the Belgian presidency when it comes to disability policy.

The first issue is that we need genuine steps throughout Europe towards the right on and the availability of personal assistance and community based services. We need a shift from subsidizing institutes and services to direct payments or personal budget systems. Can the Belgian presidency take initiative on this? Can the Belgian presidency be a leading guard and thus show the other member states how to make this policy shift?

The second issue concerns the lack of awareness, and especially the lack of scientific research and knowledge on Independent Living through Personal Assistance. Up till today, the supremacy of the

medical model has been so strong that many prejudices and misconceptions have a huge influence on the general public, on our policy makers, on professional caretakers of the disabled and even on people with a disability themselves. We can overcome these misconceptions by investing in scientific studies and research, by investing in experiments and pilot projects and by financially supporting Independent Living programs and cooperatives of disabled persons. Can the Belgian presidency increase European funding of organizations and projects of disabled people who contribute to Independent Living, and safeguard that these funds will not be misused for sustaining the medical model?

Thank you for listening.

Peter Lambregts

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