

# The Right to Live in the Community

## Seminar of the European Coalition for Community Living

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## Closing Remarks

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**Jan Jařab**  
*European Commission*  
*Member of Cabinet of Commissioner Vladimír Špidla*

Ladies and Gentlemen,

After the extremely rich, informative and inspiring speeches we have just heard, there remains relatively little new for me to say. Some of my closing remarks will therefore echo what has been said already.

In my role as representative of the European Commission, I would like to emphasize, above all, that the Commission actively supports development of flexible, sensitive and individualised services, the emphasis on quality of care, and the promotion of living in the community. As other speakers have done, I would also like to underline my preference for "community living" rather than "de-institutionalization" as the key term, because we need a positive term rather than a negative one - and because the term "de-institutionalization" may create the impression that the work of inclusion is achieved once institutions are closed, which is obviously not the case.

On a personal level, please allow me to express my highest acknowledgment and admiration to all those who are active in the aforementioned process of inclusion into the communities - service providers, NGO activists, family members and people with disabilities themselves.

Ladies and Gentlemen,

In 1897, the French artist Paul Gauguin painted a famous symbolist picture called "Who are we? Where are we coming from? And where are we going?" In closing this event, perhaps we should pause for a moment to reflect upon these three fundamental questions.

WHO ARE WE? I strongly believe that a lot depends on how we define the "we". If this "we" means only one particular interest group, or if our concept of "we" includes all stakeholders and our societies in general. From the different examples of various Member States and Candidate countries it emerges quite clearly that the best progress is achieved where this all-encompassing "we" is taken for granted - in cultures of genuine consensus, such as the one of Sweden. And conversely, that the greatest obstacles to progress occur where the different groups are most polarised into "us" and "them". Professionals versus NGOs, support groups and clients. Authorities versus the general public. Not surprisingly, this is most often the case in societies of Central and Eastern Europe, which had long been subjected to a false "unity" imposed from above. When this artificial unity disappeared, we see that it has produced polarisation around narrowly defined group interest, and a diminished capacity for genuine consensus.

WHERE ARE WE COMING FROM? In terms of *human rights*, the Europe of the recent past from which we are emerging can be described as one which shared a vision that these are above all civil and political rights, which can be taken for granted *insofar as standard, average citizens are concerned*.

Referring more specifically to people with disabilities, we are coming from a concept which saw them as more or less passive objects of care. In *ethical* terms, it was (or remains) paternalistic, as if only shifting the responsibility from no less paternalistic traditional family to public bodies and to broader society and its institutions. It was hierarchic, making no excuses for being a relationship of power. And in defining *human needs*, such a concept also was (or remains) predominantly materialistic, focusing almost exclusively on the material well-being of the people in need of care.

WHERE ARE WE GOING? WHERE SHOULD WE BE HEADING TO? In terms of *human rights*, we should be heading towards a concept wherein it is taken for granted that human rights and dignity are not dependent on being "like everyone else", that they belong to everyone, regardless of ethnic identity, health status, intellectual capacities or citizenship. In this respect, European societies - including those of established democracies - have progressed greatly over the last two decades. There are still major differences in the progress which individual European societies have made on this trajectory. And even in the most developed of our societies, there still seem to be two last categories of those who are not often seen as partaking of full human rights; there seem to be two remaining divides, a cognitive one which divides people with intellectual disability or mental illness, and a second one which considers illegal immigrants.

Concerning more specifically people with disabilities, we are moving from paternalistic to interactive ethics. Until recently, ethic textbooks for professionals in the caring professions used to be fairly simplistic, teaching about "what is good for the patient/client". Now it is a much more complex issue, because in interactive ethics there is a less clear definition of what is "good". It is far more individualized and dependent on the context, because the patient/client is to be taken as an active subject. While some aspects of power relationships may be inevitable, the aim is to minimize such hierarchic features and to promote the emancipation of every individual. Also, the focus is gradually shifting from mere material well-being to individual dignity, emotional well-being and intellectual involvement, to issues of the highest attainable autonomy on one hand, but also to the needs which peoples have as social beings.

In this context, - that of people as social beings, - it is perhaps important to underline that being outside an "institution" does not in itself guarantee that one is included in a "community", or that one has emotionally satisfying social interactions with other people. As I have observed earlier, traditional family structures also tended to be paternalistic; and indeed, recent research has shown that abuse of the elderly or disabled individuals is most common in those families which are traditionally paternalistic and hierarchic, particularly in those of lower income and education. Thus, we might venture to say that the promotion of community living does not aim at restoring a lost traditional idyll from which disabled people had been snatched away by evil public institutions. **Rather, it aims at transforming this public responsibility and at creating new communities, which are - as I have mentioned - essentially modern rather than traditional in their perspective of ethics, human rights and human needs.**

I believe that is indeed where European societies are heading to, though it must be acknowledged that there are enormous differences between them. What can the European Union contribute in this context? I would hesitate to use the word "guidance", as it is clear that the European institutions themselves are not above such social processes, and they is making

its own progress upon the aforementioned learning curve. But perhaps the Open Method of Co-ordination on long-term care could enable the Commission to take on a role of a catalyst, of making the good practices already achieved by some Member States - such as those promoted at this event - spread faster across the Union.

Thank you for your attention.