What was achieved in Lithuania for

the inclusion of people with intellectual disabilities

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I have a unique opportunity, while serving as a UN Special rapporteur on the right to health, during my travels to different countries and regions, to see all possible scenarios – success stories, failures, or most offen – combination of these two.

And when I am back to Lithuania, I am often asked – how is Lithuania doing, to compare it with other countries? Are we better or worse?

In the UN mechanisms we do not do this type of ranking. As independent experts, we assess the performance of the country in realization of human rights of everyone, and especially of groups in vulnerable situations, in this case – of children and adults with intellectual disabilities. And then, what is most important is to „make a diagnosis“. Whether this country is making progress, or there is no progress, which is sort of stagnation, or maybe regressive signs are obvious, which, sadly, also happens. And we have many tools for such assessment. The main „compass“ in the field of right so persons with disabilities is the CRPD convention.

What is special with Lithuania? This is a unique combination of achievements, failures, challenges and opportunities. First – the impressive start Lithuania has done in this field in the 1990s. I am really proud to have been among those who started then, in 1989. „Viltis“ since its birth was exercising democracy from the very first days democracy was re-established in Lithuania. It was amazing how quickly parents learned basics of what and how can be achieved, and basics of what HOPE is about. HOPE is not about miraculous medical cure. Hope about living in the country in which you know that your loved one will live in diginity also when you will pass away. And living in dignity is incompatible with living in closed institution. „Viltis“ educated politicians, teachers, doctors and all citizens about all this, and many alternatives to institutional care were then established throught the country.

„Viltis“ was for sure most successful baby of all babies I have initiated then, and the thing I am proud most of all, that I contributed to birth ofthis organization 30 years ago. Parents were much better learners, than doctors, for example. Just to compare, my another baby was Lithuanian Psychiatric Association. I am sorry to tell this, but for the professional group of psychiatrists 30 years was not enough to take a position that people should not be deprived in liberty. Human rights are still some contraversial concept to many doctors, who are trained (not only in Lithuania) i wrong way – that they know what is best to the patient, and that the main thing is to fix disorder. No, this is not true. The main thing is to ensure that children and adults with intellectual disabilities are as myuch autonomous and independents in their decisions, and that they live in supporting inclusive environment, and that they enojoy all their rights in the same way other citizen do - live with loving parents, attend school, after growin up have a place for independent living in cosy group home, have a job, have friends, enjoy leisure time. Simple as that ! But for this we need to abandon legacy of outdated mentality, with overprotection, medicalization, paternalism, charity approach being key concepts.

By the year 2000 Lithuania already had many elements of the new system, especially for children with intellectual disabilities. Early intervention services, integration of special needs children in schools, first indepedent living and occupational places for young adults, summer camps – many pilot programmes were established on the wave of enthusiasm and vision to catch up with rest of Europe. Powerful coalition of „Viltis“ and Vilnius university Child Development center made Lithuania a story of success in the broader region of Central and Easter Europe. We were planning another stage of development of services, especially after Lithuania joined the EU in 2004. But then, surprisingly, the stage of stagnation started.

Paradoxically, with joining the EU and arrival of EU structural funds, many things did not go better. EU funds to large extent have been used by supporters of outdated system to renovate many such places like segregated large long stay institutions and psychiatric hospitals. Until now Lithuania remains a country that has unacceptably high numbers of children and adults living in institutional care.

The last 15 years have been not that good as the first 15 years, and this paradox should be a lesson for us. The main thing is not financial resources. The main thing is to have a coalition of forces who are willing to move ahead towars full realization of Universal Declaration of Human Rights and the CRPD, and to liberate all of us – not only persons with intelectual disabilities and their families, but all members of our societies – from prejudices and cynical mentality. Lithuania of today is a country of missed opportunities. Everything is in out hands. We have unique opportunity to replicate existing innovations and to develop effective community based and services so that we could fully abandon legacy of institutional care. Human rights based approach is needed not only for persons with disabilities and their families. It is very much needed for general public. Only with fully integrating all people and only with ending discrimination on all possible grounds the society can be inclusive, tolerant, vibrant and healthy.