Rights of persons with psychosocial disabilities: long way from declarations to non-discriminatory policies and practices

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My decision to apply several months ago for the position of a UN Special Rapporteur on the Right to Health was very closely related to my experience, through last 32 years, as a medical doctor and university teacher and researcher, and, in fact, to the teme of this symposium.

I was somehow from very beginning of medical career sensitive to human rights issues. And then one day I started hearing around that I am not so much any more identified as a doctor or University professor. I was recognized now as a human rights activist, as a representative of civil society, with positive or negative contents put to this „hat“.

I have been told often that this is so unusual to see a doctor, a psychiatrist, an academic person, being interested in human rights, being too close to civil society and too critical to paternalistic biomedical model with doctors keeping monopoly of power and dominating the mental health scene. What I was focusing on was – I heard – not what doctors and researchers should be focusing on. Doctors, by prevailing common sense among medical profession and public at large, need to firstly cure patients by applying all available treatments, and researchers should firstly do research on how illnesses could be defeated through progress of biomedical science.

I disagree. At least on what comes first, what should be a priority. I am convinced that doctors firstly should not harm, and for this they should be firstly committed to promoting and protecting human rights of most
vulnerable people, and only then, after all necessary safeguards of protecting human rights are in place, treatment modalities, whether psychosocial or biomedical or any other, should come. Otherwise – if we do not place as a priority a rights based approach, treatment modalities, despite all good intentions, again and again will turn into systemic violations of human rights, often amounting to torture, as it happened many times in the history of psychiatry, and as it is happening today, in the 21st century, in many places globally, including European region. I am convinced that biomedical research needs to be very seriously supervised and guided by social sciences, and that quantitative research should not be considered superior to qualitative one – if we do want to hear again sad stories to be repeated such as when Nobel prize was awarded for scientific discovery called lobotomy.

I had – as all of us had - many good teachers as a medical doctor and psychiatrist, they were very good and caring teachers, but there was one thing I could not simply understand in their clinical or moral thinking. During one of my first working weeks as a young psychiatrist in training, one of my professors invited the husband of a young patient who had third in two years severe psychotic episode, and it was obvious that she is ill with chronic mental illness. My professor strongly recommended to this person to divorce his wife as quickly as possible, in sake of well-being of rest of the family. This was very painful to hear, this I could not understand, and such kind of „humanistic approach“ I still can not understand – how it comes that we doctors forget that we should care about patients and not about how to „protect from them“ others, so called healthy members of society (this was explanation I received about why this recommendation followed - „her prognosis is bad, anyway she will be sent to longterm care institution“). Well, I thought then, time is needed, and probably democracy is needed to get rid of this totalitarian ideology so that citizens are not classified anymore
into those normal, worthy of meaningful life, and those who become „hopeless“ after they receive a diagnosis of serious mental illness.

After some time, in the early 90s, my country Lithuanian and the whole region of CEE (Central and Eastern Europe) was so passionate and committed to break the iron curtain and to fight for freedom. Today, 25 years after, this unfortunate legacy of ignoring human rights of many citizens, is still so strong, and I remain sensitive and react emotionally to similar views I hear often around. We have to admit with serious concern, and I think this is why we all are here today in this meeting – despite huge achievements of many countries in the European region, despite successful EU enlargement, many European citizens are deprived of enjoying their rights and freedoms. They are deprived of liberty, staying closed in strange institutions, they are deprived of many fundamental human rights only because they have diagnosis of menl disorder. They are deprived of legal capacity, which means civil death. They are deprived of enjoying community and family life. Progress is so slow in many countries of the CEE subregion, and if any progress at all in some of them.

This painful disappointment of failure of vision after how many of us here imagined change after break of Berlin wall a quarter of century, and hope that change of paradigm is still possible, was one of main driving factors in my decision to apply for the position of UN Special Rapporteur. So then, in spring this, this year, without much thinking and hesitation, I wrote in my application:

„My views have been influenced by the fact that since 1980s I have been serving children with special needs and persons with mental disabilities. The common ground between these two groups is that doctors, managers and policy makers tend to make decisions without consulting with service users and their family members. This mistake has led in
numerous instances and in many countries to sad consequences, amounting to grave violations of human rights of children and adults. The need to apply modern human rights principles in everyday healthcare practice remains very important globally, and should be raised at the highest possible level as one of crucial right-to-health issues. Hence is one important part of my motivation“.

I am happy now to have been appointed, and I would like now, with my mandate, to join and support efforts of all of you, to address, among many other important rights to health issues, the huge problem of violation of human rights of persons with psychosocial disabilities. We have in Europe many good opportunities to reach a breakthrough, so that in this important area values and science finally prevails finally over prejudice and ignorance.

There are two sets of arguments for this sad experiment of destroying human destinies through institutionalization of persons with psychosocial disabilities to come to an end as quickly as possible. First is that what is happening with thousands of persons with psychosocial disabilities in the region, is a systemic violation of rights, and this is absolutely unacceptable for Europe and European Union, with its ambition to demonstrate global leadership in human rights. In longterm institutional care right to health (physical and mental health) is violated, as well as many related rights – economic, social, cultural, but also, - after these institutions are often renovated so that conditions are no longer appaling (so that one could tell that progress has been made with social and economic rights) – civil and political rights. Systemic violation of human rights of citizens is a very serious fact, and we should be seriously considering problem of accountability and responsibility – whether those responsible, for example, members of governments, are aware that their action, or rather inaction amounts in such case to what
might be classified as criminal negligence? Governments, health and other ministers should be at least aware that they are accountable, especially after the UN CRPD has been ratified.

Another set of powerful arguments comes from research. There is abundant evidence, and all this new evidence comes from modern public mental health approach, that the most possible ineffective way to manage psychosocial disabilities is to invest into longterm institutional care. Detrimental effect of such „methods“ - when helplessness and dependency in persons is strengthened, and not autonomy and participation, as it should be, is actually larger, than effects of chronic mental illness as such. So prognosis of that lady from my story was and in mny countries remain really bad, but not because of her illness, rather because of our self - fulfilling prophecy and subsequent institutionalization, because everybody decided so around that she is not a human being any more, she is now schizophrenic.

We have to end with this sad tradition. On 10th of October 2014 UN Secretary General Ban Ki-moon said – Suffering from schizophrenia should not have to mean enduring “a life sentence of isolation and poor physical health,” as he urged the creation of better support networks and services for people living with the mental health disorder.

But here I would like to bring another powerful and often neglected perspective – that of modern public health. I would like to highlight the fact that legacy of institutionalization is harmful not only to persons who suffer from this unfortunate tradition (maybe time to qualify it as harmful practice?). Evidence from sociology, social psychology, public health demonstrates, that societies which close themselves in vicious cycle of stigma, social exclusion, violence, helplessness, hopelessness, - these societies of so called very normal people punish themselves - so we witness in the region of CEE still continuing unprecedented
epidemics of self – destructive behavior, with very high rates of suicides, other premature deaths, violence, alcohol abuse. In this, as in any other vicious cycle, each component is both cause and consequence, and so is with sad legacy of excessive institutionalization. This phenomenon is effect (outcome) of outdated beliefs and attitudes of major stakeholders, of failed health and social policies. At the same time this phenomenon, instead of solving problems, creates a lot of new ones, adding to further escalation of vicious cycle.

So if „normal“ people continue to think that it is OK that they take care of only their own rights, and for the time being they are allowed to ignore and to sacrifice human rights of vulnerable groups, such as persons with psychosocial disabilities – they are wrong. With such selectivity of human rights society and citizens are inevitably punishing, in the long run, themselves. Societies in the region continue paying high price of population equipped with unhealthy defensive mechanisms such as intolerance to others.

So, what is the problem that these two powerful sets of arguments do not properly work so far in many European countries? We will here today many good practices, and this is good news. The problem however, remains that these are still often just good exceptions from the rule, and the rule is that institutional care is still flourishing, with national budgets, EU funds and huge human resources supporting and reinforcing this self-feedingsystem. We have to admit – values and evidence is still often losing to ignorance, irrational fears, severely disturbed (by prejudice an stigma) common sense and corrupted interests of those who control and support such system. We need to continue strengthening open discourse on this sad page of European reality. We need to increase critical mass of those committed to end up with humiliation of thousands of Europeans, and with justification of this grim situation.
I also think, being proud of being a European, that Europe has a special obligation here, with its longstanding commitment to liberal democracy and universality of human rights. It cannot remain so, that in 21st century we find ourselves in Europe discussing which option is better or worse for patients – cage beds or massive chemical restraint, keeping people closed in institutions housing 400 persons, or housing after renovation „only“ 200 persons.

Many good do’s and dont’s will be presented here today and tomorrow. We know that problem like this can and must be solved not through search of magic bullet, but through concerted efforts of the willing to commit to change To break vicious cycle, we sometimes need breakthrough in just one of many good recommendations we will be hearing today. I want to draw our attention and invite you to discuss on three decisive stakeholders and how to take them on board, on our side. These are policy makers, professional groups (psychiatrists especially) and general public. They all need to be addressed with very clear message that it is also in their interests and their reputation to decide whether they are on the side of progress or regress.

I wish all of us a good and fruitful symposium, and I want to end with words of Navi Pillay, former UN High Commissioner of Human Rights, who just recently ended her term in the office, one of the best human rights advocate I know:

“We cannot weigh rights. We only have universal rights, no Asian rights, African rights, western rights, traditional rights. Pain is pain and everyone feels it no matter where it occurs”.

With this pain, and with appeal for committing to change, I address you, as I will be addressing important decision makers throughout the world, when carrying out my mandate.

Thank you for your attention.