

US UPR 2010 listening session March 26, San Francisco

My name is Sylvia Caras. I'm an early technology adopter, the founder of a 15 year old electronic community for people who cope with mood swings, fear, voices and visions.

I've been in six psychiatric hospitals, three times against my will, three years altogether, handcuffed, electroshocked, chemically restrained, deficits explored by counselors, I didn't like any of it.

From the perspective of this review, there are bold and there are subtle indignities. I learned how disrespectful handcuffs feel. Some think forced mind-altering attention meets the international standards of torture. Most involuntary institutions restrict use of telephones, few provide web services. Because we delegate transport to the police, I have a record that displays whenever an employment background check is run.

When the United States signs the Convention on the Rights of Persons with Disabilities we must as well honor its careful crafting. For the wants of people with psychiatric diagnoses are diluted by so many others who claim to be stakeholders, who want to share, well really direct, instead of support our decision making.

But the most sly, the most subtle deprivation is that I'm stripped of responsibilities, and that deprivation is based on my diagnosis of disability. I'm encouraged to only join low-stress activities, to ask for help to manage myself, and at the extreme I'm not allowed to vote or to sign contracts. Rights have to do with liberty, and mine can be curtailed. Duties have to do with dignity; but I'm asked for few.

We people who cope with mood swings, fear, voices and visions are consistently denied many of the rights enumerated in the Universal Declaration of Human Rights, so that it seems those rights don't fully attach to us, that we are invisible, or an exception, a yes, but ...

There is no but. The rights of the UDHR are fundamental. They are not entitlements; they are not reversible. They are meant to include me too.

So, what to do?

Education and access.

In order to exercise my rights I need to know what they are. Continue the broadband initiative and create electronic accessibility for full inclusion in the knowledge society. Emphasize critical thinking starting in grade school. Require transparency, including industry-funded health non-profits and web sites.

For my disability in particular, the psychiatric diagnostic manual is being revised. Amidst controversy. The “Clinical tensions mask social and political ones.”¹ “As if to demonstrate the point that the creation of mental illness categories remains as much a social and cultural endeavor as a scientific process, the APA is soliciting input from the public [for DSM-V].”²

We change the paradigm by changing the language.³ Not medical. Not criminal. Words do matter. Use words that truly presume “wellness, response-ability and the value of the person’s interpretation of their own experiences”⁴

Include me too.

1. Jonathan Metzger, *Protest Psychosis*, 2009. Beacon Press, Boston, p 192.
2. Ethan Watters, *Crazy Like Us: The Globalization of the American Psyche*, 2010. Free Press, p 252.
3. <http://www.peoplewho.org/documents/mediaguidelines.htm>
<http://peoplewho.org/documents/wordsmatter.htm>
4. <http://www.mentalhealthpeers.com/>