

RIGA 2023 CONFERENCE  
ENSURING RESPECT FOR  
AUTONOMY IN MENTAL  
HEALTHCARE



**“Autonomy in theory and practice: patients’ perspective”**

**Stephanie Wooley**, Deputy Board member, ENUSP -  
European Network of (Ex-)Users and Survivors of Psychiatry  
Board member in charge of international relations, Advocacy-France

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**Conference of States Parties to the UN CRPD - New York – July 2018**



**Survivors of psychiatry advocating for our cause:**

**Tina Minkowitz**, Human Rights lawyer, CHRUSP, New York, USA


**Hege Orefellen**, Human Rights lawyer, We shall Overcome, Norway

**Kweon Ohyong**, Human Rights lawyer, Korean Alliance on Mental Illness, South Korea

**Jolijn Santegoeds**, Co-Chair WNUSP, Board member ENUSP, Mind Rights, Netherlands

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## European Network of (Ex-)Users and Survivors of Psychiatry





Only European independent federation exclusively composed of and representing (ex)users and survivors of psychiatry, created by the grassroots in 1990.

Major expertise with 36 member organizations and 50 individual members in 28 European countries.

Impressive network of allies and partners (EDF, MHE-SME, EASPD, Validity Foundation, Human Rights Watch...)

Advocacy / awareness and action against all forms of coercion in psychiatry: international and European bodies– OHCHR, UN CRPD Committee, WHO, FRA, European Parliament and Commission, Council of Europe...

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## Just a reminder :

- UN CRPD, Article 4 requires States Parties to assume their obligation to reform laws that are not in compliance with the Convention – they must engage in consultation and involvement of representative organizations for this purpose.
- General Comments and Guidelines (such as on Art. 14) are authoritative even if not binding on States – they are expected to have weight and cannot be considered simple interpretations or opinions. States cannot “play the judge and the party being judged” to decide that their laws are in compliance with the Convention.

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## High time for a change of paradigm –



- UN CRPD Committee – excerpts General Comment no. 1:

“**States parties must abolish policies and legislative provisions that allow or perpetrate forced treatment**, as it is an ongoing violation found in mental health laws across the globe, **despite** empirical evidence indicating its lack of effectiveness and the **views of people using mental health systems who have experienced deep pain and trauma as a result of forced treatment**. The Committee recommends that States parties ensure that decisions relating to a person’s physical or mental integrity can only be taken with the free and informed consent of the person concerned.

Forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement of the rights to personal integrity (art. 17); freedom from torture (art. 15); and freedom from violence, exploitation and abuse (art. 16). **This practice denies the legal capacity of a person to choose medical treatment and is therefore a violation of article 12 of the Convention.**

States parties must instead respect the legal capacity of persons with disabilities to make decisions at all times, **including in crisis situations**; must ensure that accurate and accessible information is provided about service options and that non-medical approaches are made available; and must provide access to independent support.”

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## Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, June 2017, Dainius Puras, child psychiatrist

“ ... The problem is not in diagnosing persons but in the discriminatory practices that affect the diagnosed person, which may cause more harm than the diagnosis itself. **People frequently suffer more from discriminatory and inappropriate patterns of “care” than from the natural effects of mental health conditions.**”

“Considering that the right to health is now understood within the framework of the CRPD, **immediate action is required to radically reduce medical coercion and facilitate the move towards an end to all forced psychiatric treatment and confinement.**

In that connection, **States must not permit substitute decision-makers to provide consent on behalf of persons with disabilities on decisions that concern their physical or mental integrity;**

instead, support should be provided at all times for them to make decisions, **including in emergency and crisis situations.**”



Mad Pride Paris, 2014

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#### THE WORDS AND FEELINGS OF A PEER ON HER EXPERIENCE WITH PSYCHIATRIC COERCION

SI C'EST CONTRAINT



C'EST PAS DU SOIN

COERCION IS  
NOT CARE

"It seems to be a futile struggle between small and great – the 'clay pot versus the iron pot'. The medication I'm taking doesn't encourage me to take action, even if, as a victim of psychiatry, there's a wind of anger inside me blowing against this inhuman system....

But as a psychiatric patient, I'm still in the hands of psychiatrists, so I'm powerless and far from having full freedom of speech. After 3 years of fighting with several psychiatrists, I managed to get the anti-psychotic injections replaced by an oral treatment. I can see that the psychiatrist who agreed to this change and who is assigned to me has very little trust in me.

... To really know what it's like to be caught up in psychiatry, you have to be a victim of it, to have suffered the mental torture and coercion that has been put in place, and to know the feeling of fear that this discipline engenders. **As a user, psychiatry has taught me three things: contempt, fear and a feeling of powerlessness and insecurity.** You have to understand that the mere sight of a police car driving by, or the sound of a fire engine or ambulance siren, sends a wave of panic through me and makes my heart beat faster, such is the trauma of the forced hospitalizations I have undergone...".

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#### Statement made by Dainius Puras when delivering his report to the Human Rights Council

"Power and decision-making in mental health policy, services, and care structures is concentrated in the hands of biomedical gatekeepers, particularly biological psychiatry. These gatekeepers, reinforced by the pharmaceutical industry, maintain this power based on **two outdated and scientifically unsound concepts: that people experiencing mental distress and diagnosed with "mental disorders" are dangerous, and that biomedical interventions in most cases are medically necessary.** These concepts perpetuate stigma and discrimination, as well as practices of coercion that are widely accepted in mental health systems today."

"I see the global state of mental health **not as a crisis of chemical imbalances but a crisis of power imbalances, requiring urgent policy responses to address the social determinants of mental health as well as the reflection of powerful stakeholders on their role in perpetuating an abusive status quo.** In other words, the crisis in the field of mental health should be managed not as a crisis of individual's conditions or disorders but as **a crisis of societal obstacles that hinder individual rights.**"

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### Report of the UN High Commissioner for Human Rights on “Mental health and Human Rights”, Zeid bin Ra'ad bin Zeid al-Hussein, Jan 2017

Forced institutionalization violates the right to personal liberty and security, understood as freedom from confinement of the body and freedom from injury to one's bodily or mental integrity, respectively. It amounts to a violation of the right to live free from torture and ill-treatment, and from exploitation, violence and abuse, and of the right to personal integrity. States parties should repeal legislation and policies that allow or perpetuate involuntary commitment, including its imposition as a threat, and should provide effective remedies and redress for victims.

In certain situations, the will of the person concerned might be difficult to determine. Instruments such as advance directives or powers of attorney should be promoted and clearly formulated to prevent misunderstanding or arbitrariness by those executing them. Even when such instruments are in force, persons with psychosocial disabilities must always retain their right to modify their will and service providers should continue to seek their informed consent.

The CRPD Committee has held that, in all cases, it should be understood that article 12 of the Convention on the Rights of Persons with Disabilities prohibits resorting to the principle of the “best interests” of the individual in relation to adults with disabilities. Significant efforts must be made to determine the individual's will and preferences, ensuring that all possible accommodations, supports and diverse methods of communication are made available and accessible.

Where all means have been exhausted and the individual's will remains undetermined, the principle of “the best interpretation of will and preferences of the individual” must be upheld and carried out in good faith.”

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## ENUSP's position (1)



Depriving persons of legal capacity on the basis of a psychosocial disability and a psychiatric diagnosis leading to forced psychiatric interventions:

- **is not care**, does not result in wellbeing.
- **disables care**, undermines care-relations.
- **does not result in safety**, results in more struggle, more crisis and more risks.
- indicates the **deficiency and failure of mental health care with no adequate support in crisis**.

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## ENUSP's position (2)



Forced psychiatric interventions:

- **Enable neglect** and undermine development of good support practices.
- **Are not evidence-based or recovery-oriented**, but remnants of the past.
- **Are not protection**, but are abuse.
- **Are not a solution**, but are a problem.

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## ENUSP's position (3)



- **Real and acceptable mental health care is possible when efforts are made!**
- **Many options between "last resort" and "no care"**
  - **Supportive interventions:**  
De-medicalized, de-judicialized crisis support and response to conflict  
De-escalation and responding to violence  
Decision-making support for personal crisis
  - **Prevention:**  
democratizing knowledge,  
building and strengthening community accountability, support and practices  
(social and solidarity economy)
- **Real development of mental health care and support based on equality, and the person's will and preferences is urgently needed.**

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## IN CONCLUSION

- Users, ex-users and survivors of psychiatry are "Experts by experience" and must play a vital role in ending this imbalance of power.
- Services and legislation must be based on free and informed consent, without coercion or substitution of the right to decide on one's own life, in accordance with the Convention.
- An obvious challenge for our health care systems, social services and our criminal law regimes - Human and financial investment in these areas is absolutely essential.

**The UN CRPD calls for a change of paradigm long demanded by persons with psychosocial disabilities who have experienced deprivation of liberty, forced treatment, guardianship and institutionalization.**

**We must share and learn from our experiences to reach these international human rights standards for everyone in Europe and the world.**

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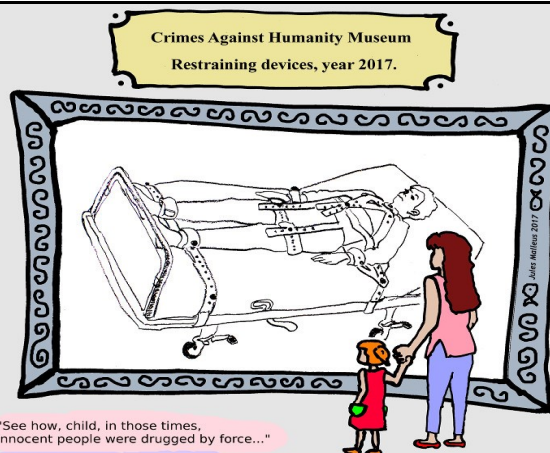
ENUSP's vision of the future...

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Artist: Jules Malleus,  
ENUSP individual member, France



"See how, child, in those times, innocent people were drugged by force..."

"Why would they do that, mom?"

"It was considered standard practice in many countries... People believed it was care... It was supposed to help, to protect, for safety... Everything was based on falsities, prejudices... There was fear too... Speaking about this was a social taboo."

"That is horrible, mom!"

"Yes. But fear not, love. It was abolished. These practices exist no more."



UN Convention on the Rights of Persons with Disabilities: Absolute Prohibition of Commitment and Forced Treatment

Help make the prohibition effective. Please share this meme with your friends. For today's victims and for tomorrow's.

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