



ENUSP Feedback on the WHO Europe Indicators of empowerment

WHOECG Congress on

"How to promote empowerment experiences of mental health service users and carers in Europe?" Indicators and good practices

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Piotr Iwaneyko: ENUSP has been active for over 20 years and ENUSP-representatives were involved in the early stage planning of the Convention on the Rights of Persons with Disabilities (CRPD) at UN level. Several members of ENUSP have developed good practices, such as the Personal Ombudsman from Sweden, Family Group Conferencing in the Netherlands, large-scale user involvement projects in a National Policy Forum in Romania, and also in Romania: a User-run village of national houses. And in Spain and France: Peer-Advocacy and Peer train-the-trainers programmes. More information can be found at the end of this document and on our website: www.enusp.org



Jolijn Santegoeds: ENUSP has been asked to comment on the indicators of empowerment as developed by WHO Europe. We were not meaningfully involved in designing these indicators, but if we had been, we probably would have done it differently: We would have taken the Convention on the Rights of Persons with Disabilities (CRPD) [1] as guidance. The CRPD is the current international human rights standard, which sets out the human rights of persons with disabilities, including the rights of persons with mental or psychosocial disabilities. ENUSP would have reflected on that.

[1] <http://www.un.org/disabilities/index.asp>

The current indicators of WHO Europe are grouped in 4 themes:

1. protection of human rights
2. inclusion in decision-making
3. high-quality care and accountability
4. access to information and resources

1. With regard to theme 1: protection of human rights

According to WHO Europe, this relates to having the right to vote, to hold public office and that there shall be no discrimination in legislation on employment.

ENUSP is of opinion that this is a very narrow and incomplete view on our human rights.

The CRPD is clear about the substance of our fundamental human rights. There shall be **no forced treatments and no forced institutionalization** which falls within the scope of freedom from torture [2], and under the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention Against Torture (CAT). This includes banning solitary confinement, constraints, forced drugging and general confinement based on a perceived or actual diagnosis or disability. As a clear illustration: Forced Community Treatment or any other forced treatment, is the opposite of empowerment. This is a clear indicator.

2. With regard to theme 2: inclusion in decision-making

According to WHO Europe, this relates to involvement and having authority in design and implementation of services.

ENUSP misses the word "meaningful" in involvement. Often user/survivor involvement is tokenistic and not meaningful in terms of having real influence and effects from involvement and changing the outcome of the process we're involved in.

Also about decision-making, the CRPD is clear. There is a prohibition of substitute decision-making and a right to legal capacity (self-determination) under Article 12 of the CRPD. This means there can be **no guardianship-regimes and no substitute decision-making**, but people have the right to a free choice about their own life, including choice of residence and treatment. The right to choose includes the option to say no and to refuse treatment. Again these are very clear indicators.

The CRPD was the first UN Convention to ever have been ratified by the European Union together as a whole, and has since been ratified by 25 out of 28 countries of the European Union. And the European Court of Human Rights recently stated that persons have "the right to be ill" [3]. The CRPD makes clear

[2] A/HRC/22/53 Mendez (2013)

www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

[3] *Plesó v. Hungary* 41242/08 (2012) <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-113293> and: www.law.harvard.edu/news/2012/11/15_disability-rights-echr-hpod-assoc-fiala-burtora.html

that disability doesn't make you less human, and that you are entitled to all human rights. **Self-determination or legal capacity is a gate to all other human rights.** Without the right to make decisions, you cannot choose where to live, get married, have children or make a complaint and so on.

3. With regard to theme 3: high-quality care and accountability/evaluation

According to WHO Europe, this relates to inspection, monitoring, planning and review of your own care and access to general health services, and involvement in the training of staff.

ENUSP states that high-quality care should benefit the user, so the indicator should be **satisfaction according to users**, as it is about the users' wellbeing. Important aspects are for example the amount of choice: how many available alternatives are there? Is there any community based care?, Is this care individually tailored? Are there conditions, as in conditional support? Is there an additional burden (eg., financial?)

There are many **User-defined Good practices**, which should be made available, since there is a Right to adequate care, as in the highest achievable standard of health and health care.

When it comes to accountability and evaluation: Having an actual or perceived psychosocial problem, diagnosis or disability is not a choice, so there should be no negative consequences attached. We have the right to be treated well, with respect, and **independent monitoring** is needed (often monitoring is not independent). Monitoring and inspection should include users (Article 33 CRPD).

4. With regard to theme 4: access to information and resources

According to WHO Europe, this relates to getting access to your own medical file and whether there is legal support.

ENUSP interprets the right to information as being a right to **full information**, not just access to one's own medical file, but also access to information on other options, and information on the risks of medication for example. And the right to consult with the people of your own choice, and so on.

Regarding the **legal protection of users' rights**, important indicators are: Are complaint procedures accessible and effective? Can any user complain about anything (or is it limited)? How many successes and adequate remedies have there been? (we know that they are generally very few), Is there access to legal support to make complaints? Does this support come from NGO's or is it governmental?

On access to resources, this also relates to **social status and stigma** (such as access to finances, housing, work, etcetera).

So to conclude:

Many concrete indicators can be derived from the CRPD in close consultation with users. However that has not yet been done in these set of indicators proposed by WHO Europe.

Many of these indicators are linked to the policy and legislation level, and don't really focus on the lived experiences of users. However, human rights are not just policy lines. Human rights are about the real experiences of people, their real rights.

But nevertheless, we would like to conclude with the following statement from our perspective: "It is easier to improve something than to start something".



Drawing made by the cartoonist of the WHOECC Congress:
Jolijn Santegoeds: "I have the right to have the right"