

Joint Submission by:

The Romanian Angel Appeal Foundation

&

ACCEPT Association

&

The Romanian Association against AIDS (ARAS)

&

Carousel Association

&

The Association for Supporting MDR-TB Patients (ASPTMR)

&

ECPI-Euroregional Centre for Public Initiatives

&

The Baylor Black Sea Foundation

&

Save the Children Romania

&

The National Union of Organizations of People Living with HIV/AIDS (UNOPA)

&

Romanian Harm Reduction Network (RHRN)

&

Center for Health Policies and Services (CPSS)

SUBMISSION PREPARED BY The Romanian Angel Appeal Foundation, ACCEPT Association, The Romanian Association against AIDS (ARAS), Carusel Association, The Association for Supporting MDR-TB Patients (ASPTMR), ECPI-Euroregional Centre for Public Initiatives, The Baylor Black Sea Foundation, Save the Children Romania, The National Union of Organizations of People Living with HIV/AIDS (UNOPA), Romanian Harm Reduction Network (RHRN), Center for Health Policies and Services (CPSS)

FOR THE UNIVERSAL PERIODIC REVIEW OF ROMANIA BY THE HUMAN RIGHTS COUNCIL –3rd cycle 29th Session

KEY WORDS: Discrimination on the basis of HIV status; sexuality education; right to health; right to privacy; rights of the child

INTRODUCTION

1. This compilation of information has been produced in June 2017 by the group of organizations above-mentioned who advocate for equal right to health for all, including persons belonging to vulnerable categories. The crosscutting element of this submission is the concept that the enjoyment of the right to health must be ensured for all, without discrimination. The focus of the submission is on vulnerable categories of people that are often subjected to multiple forms of discrimination – women living with HIV, adolescents, children, homeless people, people who inject drugs and persons affected by tuberculosis.
2. The submission is relevant for the implementation of the following recommendations accepted by Romania at UPR 2013: 109.44 (Cuba), 109.71 (Austria), 109.56 (Holy Sea), 109.48 (Costa Rica), 109.45 (Australia), 109.65 (Brazil), 109.111 (Netherlands), 109.112 (Slovenia), 109.31 (Ecuador).

The right to privacy, the right to health, the right to non-discrimination: Recommendations nos. 109.44, 109.71, 109.56, 109.48, 109.45, 109.65.

3. The rights of persons living with HIV/AIDS

- The lack of a national HIV framework since 2007 and failure to reinstate the National AIDS multi-sectorial Commission, while HIV incidence is growing among vulnerable groups and harm reduction interventions are not funded at national scale¹.
- The lack of coordination between policy and programmatic response to HIV/AIDS and the National Public Health Strategy 2014-2020 undermines the coverage and sustainability of harm reduction services that are not implemented at national or regional scale.
- The current National HIV Program is not actively implementing the new approaches on HIV prevention (PREP, PEP, treatment as prevention) and also not targeting MSM (men having sex with men), despite the fact that it is one of the most affected population group, while no HIV prevention interventions are implemented at national or regional level. Additionally, the budget available is insufficient for ensuring HIV monitoring (CD4, VL, resistance profile) in accordance

with the national and international guidelines. Other types of routines screenings are not addressed.

- The drug procurement scheme based on a decentralized system leads to inconsistencies and gaps affecting access to treatment and health care of patients who are covered by the ARV treatment.
- Healthcare units' refusing to treat women living with HIV for obstetrics and gynecological healthcare needs is leading to cases when patients do not get adequate medical treatment, resort to self-medication or unsafe abortion, are exposed to discrimination and do not declare their HIV status when accessing future healthcare services.
- Cases of discrimination against persons living with HIV in healthcare services remain unpunished and unrecognized.

4. Recommendations:

- ✓ To adopt and allocate a budget for the National Strategy on HIV/AIDS and for the National Strategy on Sexual and Reproductive Health and Rights.
- ✓ To insure that the HIV/AIDS National Commission is efficiently working.
- ✓ To sanction violations of the *Law on Patient's Rights*, including the right to confidentiality and non-discrimination on the ground of HIV positive status.
- ✓ To take measures to regularly ensure information and training of the medical personnel from all levels on HIV (including universal precautions and nosocomial transmission of HIV) and *HIV during Pregnancy Clinical Guide*, patients' rights in general, sexual and reproductive rights of the persons living with HIV, develop communication skills and non-discriminatory attitudes.
- ✓ To ensure access to HIV free testing for all medical personnel.
- ✓ To improve cooperation between health care units, medical services, or national programs (HIV and TB) in order to provide quality services in situations when an interdisciplinary approach is needed to handle patients with HIV and other comorbidities (HCV, TB, cancer), cases of pregnant women living with HIV family planning, ob/gyn, cervical cancer screening).
- ✓ To adopt legislation that allow ministries and state agencies to subcontract social and medical services targeting vulnerable populations to NGOs.
- ✓ To adopt legislation that grants access to HIV testing without parental consent below 18 years of age.

5. The rights of people who inject drugs (PWID)

- The current National Drug Strategy 2013-2020 implemented by National Antidrug Agency lacks financial support and operational plans for scaling up HIV/AIDS prevention interventions at national or regional level targeting people who inject drugs (PWID), despite the fact that this group represents one of the most affected key populations.
- The harm reduction interventions are excessively based on external donors despite the fact Romania is a member state of the European Union, and cannot cover the funding gap for services with direct effects in decreasing of the already limited harm reduction interventions².
- Access to the treatment of drug-related infectious diseases remains difficult for those with chronic Hepatitis C, while access to opioid substitution treatment (OST) remains poor³.
- Prevention information is mainly oriented towards diagnosis, and is not focused on information and education provisions, and access to adequate prevention measures.

6. Recommendations:

- ✓ To apply a human rights-based approach to PWID so that they do not forfeit their basic rights to health and social services⁴.
- ✓ To strengthen access to OST, scale up the methadone maintenance treatment and increase overdose prevention through take-home naloxone programs and the opening of safe consumption facilities in capital and major cities.
- ✓ Increase and subsidize the needle and syringe programs at national level.
- ✓ Introduce a national funding mechanism that allow civil society operators to provide subsidized services from national sources that meet the needs of people who inject drugs⁵.
- ✓ Make available HIV and Hepatitis C tests and treatment by integrating these services with harm reduction programs.

The rights of the child: Recommendations nos. 109.111, 109.112, 109.31, 109.43

7. Teen pregnancy

- Teen pregnancy remains an area of concern. According to EUROSTAT data, Romanian adolescents make one third of births by girls under 15 years old in the EU-28 (676 live births, representing 34.73% of EU 28) and almost one third of all births of girls of 15 years old in the EU-28 (28.43%). The live birth rate for under 20 year olds is the highest in the European Union (14.07% in 2015). According to EUROSTAT data, in 2015 alone, 9291 girls gave birth. 676 of them were under 15 years old. Many of the underage mothers have more than one child before turning 18. Out of the 9291 child-mothers, 1072 were at the second birth and 98 at the third.
- Sexual and reproductive health education in schools is provided on a limited scale and there is no publicly available evaluation of its impact – less than 6% of pupils study in school “Education for Health”, an optional subject that contains some information on sexual and reproductive health.
- According to the law, parental consent for accessing sexual and reproductive health care services is required until 16 years old,⁶ although the legal age of consent for sexual relations is 15 years old.⁷ Nevertheless, in practice, health care providers require parental consent until 18 years old.

8. Recommendations:

- ✓ To adopt the National Strategy on Sexual and Reproductive Health and Rights.
- ✓ To take measures to prevent teenage pregnancy and ensure services for supporting teenage mothers to continue their education and have access on the labor market.
- ✓ To include mandatory comprehensive sexual and reproductive health education in schools.
- ✓ To engage into developing the capacity and establishing competences of professional orientation and counseling centers, social workers, child workers, and family planning centers to monitor, identify and assist the cases at risk of school abandonment, child marriage, and early pregnancy.
- ✓ To immediately take firm measures to redress rights violations and ensure protection of children involved, according to the principle of best interest of the child: sanctioning the persons responsible for breaching the law and endangering the health and rights of the children, providing individualized counseling and assistance to the victims of child marriage, domestic violence, sexual violence, and providing counseling to children with regards to continuing their education, professional opportunities, child rearing, etc.

9. Sexuality education

- Sexuality education in Romania continues to be a controversial topic, despite the fact that this education is critically important to the pupils' psychological, mental and social development and empowers them to understand and claim their sexual and reproductive rights. It is not properly addressed by the authorities, politicians or media during the public discourse because it is still considered a taboo.⁸
- Sexuality education is not a subject in the Romanian public education curricula. The curriculum of "Education for Health" subject, included in the curricula in 2004 by Ministry of Education, contains a list of issues on sexuality education taught throughout the grades I-XII. However, this is an optional subject at the school's decision. Hence it is mostly not pupils' choice to study Education for Health, but rather an administrative decision of the headmaster accommodating the need for working hours of various teachers. Furthermore, Education for Health comes in competition with other optional subjects at school's decision – computer sciences, sports, etc. Thus, less than 6% of all pupils study Education for Health.
- As a practice, Education for Health is taught by biology teachers. Without training and skills for teaching issues related to sexuality education, it is not rare that teachers are reluctant to talk about issues connected to puberty and sexuality, hence they often prefer to talk about health in a general way and leave out the sex related subjects. Moreover, sexual orientation, gender norms, gender identity, preventing unwanted pregnancies, and accessing safe and legal abortion are not discussed and explored.
- Not surprisingly Romanian youth believe that the teachers who handle sexuality education at schools do not have the necessary skills and knowledge while the information they receive is not rights-based and age-appropriate. As schools don't provide the young people with the knowledge on sexuality and the parents are too reluctant and afraid to talk about these issues, young people often turn to peers, media and Internet for knowledge on sex.

10. Recommendations:

- ✓ To take steps to ensure sexuality education is compulsory and mandatory in all schools.
- ✓ To ensure that the content of sexuality education curricula is evidence-based, gender sensitive, non-discriminatory and in accordance with other international standards.
- ✓ To ensure that topics such as sexual orientation, gender norms, gender identity, preventing unwanted pregnancy and accessing safe and legal abortion are addressed in an accurate and non-discriminatory way in school curricula.
- ✓ To appropriately train and educate teachers on sexuality education – to create a national network of educators on sexuality education, educators trained through a national training program.

11. The rights to health and non-discrimination for vulnerable groups: Recommendation no.109.48 **The rights of people affected by tuberculosis (TB).**

- Although the TB control registered important progress over the last 13 years, this progress is mainly due internationally supported programmes, NGO involvement and continuous efforts of the TB medical staff.
- The high number of people affected by tuberculosis is making Romania the E.U. member state with an incidence five times above the average and also one of the lowest rates of treatment success⁹, despite the adoption of the National Strategy for Tuberculosis Control 2015-2020 and multiple interventions and support of international donors.
- Romania has the highest number of drug-resistant TB cases in the EU and an estimated number of deaths from TB almost seven times higher compared to EU/EEA average (5.5%ooo, respectively 0.8%ooo–data for 201410), although TB deaths decreased in Romania from 6 %ooo in 2012 to 5.3%ooo in 2015. The most TB affected population groups are in rural areas, in poorer regions, men, Roma and homeless people. More than 650 children are affected by TB every year (about 4.3% of all new cases).
- The access to modern, internationally recommended molecular diagnosis tools that can offer a rapid and complete diagnosis is available only through international support which contributes to low detection and diagnosis of the cases of drug resistant and extensively resistant tuberculosis.
- Even for those diagnosed, access to a complete, constant and quality treatment remains a significant obstacle: therefore treatment default rate (patients lost to follow-up) is extremely high between 4.8% for the new cases with sensitive TB and 16.6% for those with resistant tuberculosis)¹¹.
- Access to timely and complete treatment for multidrug resistant TB and extremely resistant is still limited: most of the M/XDR TB needed drugs are considered off-label and/or not registered in Romania; therefore they cannot be procured and/or reimbursed from public sources/MoH funds¹².
- Excessively hospital-centered, the health system is severely underfunded and raises obstacles in front of the universal access to treatment, psychosocial support and services especially for people affected by TB coming from vulnerable groups – such as poor people. This leads to increase in treatment abandon, very low cure rates and death.
- The TB surveillance system is poorly equipped and confronted with the lack of educational resources and interventions to dismantle the current societal culture that favors prejudice, stigma and reluctance to report symptoms.

12. Recommendations:

- ✓ To operationalize and increase domestic funding for the National Strategy for Tuberculosis Control 2015-2020;
- ✓ The implementation of the National Strategy for TB Control for 2015-2020 should be supported by the Government of Romania with sufficient and sustainable funding, and necessary changes in the health system. Aspects requiring immediate action include access to adequate treatment regimens and uninterrupted supply¹³ of TB drugs for MDR/XDR TB, ambulatory treatment and social support of patients, diagnosis and infection control.
- ✓ To introduce a national funding mechanism that allow civil society operators to provide subsidized services from national sources that meet the needs of people at risk and/or affected of TB.

- ✓ To adopt the proposed draft legislation on TB concerning universal access to proper diagnosis, hospitalization, treatment and patient centered care, ambulatory treatment and quality support for adherence to treatment to all people affected by TB, irrespective of their status¹⁴.
- ✓ To adopt and apply the WHO Guidelines for treatment of drug susceptible tuberculosis and patient care¹⁵, and the international recommendations for treatment of drug susceptible and drug resistant tuberculosis and patient care¹⁶.
- ✓ The Central Management Unit of the National Tuberculosis Program requires capacity strengthening (more human resources and adequate funding) to perform its duties such as: regular monitoring, drug procurement and supply management, methodological support for the NTP network, etc.
- ✓ Consider introducing an update of the National Guidelines for Program Management of Drug-resistant Tuberculosis (PMDT) in line with recently released recommendations by the WHO on PMDT, especially on new groups of TB drugs and regimen design for M/XDRTB.¹⁷
- ✓ The National Tuberculosis Program has to apply the human rights principles, reduce stigma and implement gender sensitive interventions. To scale up access to Education for Health discipline in the public educational system as an educational tool for preventing and combating stigma and discrimination related to TB status.

¹ Viata medicala, No. 24 (1430), "Cascada îngrijirilor HIV în România", article, http://www.viata-medicala.ro/Cascada-ingrijirilor-HIV-in-Romania.html*articleID_11409-dArt.html

² Carusel Association, Policy Paper on access to health care: <http://carusel.org/blog/policy-paper-accesul-la-acte-de-identitate/>; <http://carusel.org/blog/wp-content/uploads/2015/12/policy-paper-acte-de-identitate.pdf>

³ <http://www.harm-reduction.org/sites/default/files/pdf/romania-global-fund-eng-2016.pdf>

⁴ Carusel Association, "Abuses against vulnerable groups": <http://carusel.org/blog/un-pacient-acuza-patru-jandarmi-ca-i-au-pus-viata-in-pericol/>; <http://carusel.org/blog/scrisoare-deschisa-nesemnata/>; <http://carusel.org/blog/dinte/>

⁵ NGOs Open letter to the mayor of sector 5 of Bucharest, <http://carusel.org/blog/54-de-organizatii-au-transmis-astazi-primarului-sect-5-daniel-florea-o-scrisoare-de-protest-impotriva-deciziei-primariei-de-a-evacua-centrul-caracuda-din-ferentari/>; <http://carusel.org/blog/wp-content/uploads/2017/04/Scrisoare-de-protest-%C3%AEmpotriva-deciziei-de-evacuare-a-centrului-Caracuda.pdf>;

⁶ See Art.650 of the Law 95/2006 regarding the reform in the field of health care.

⁷ See Art.198 of the Penal Code.

⁸ 67 NGOs' Call to the Ministry of Education for introducing sexuality education in schools, available at <http://www.hotnews.ro/stiri-esential-20451688-apel-pentru-introducerea-educatiei-sexuale-scoli-adresat-ministerului-educatiei-pest-60-ong-uri.htm>.

⁹ European Center for Disease Prevention and Control, World Health Organization Regional Office for Europe, Tuberculosis surveillance and monitoring in Europe 2017, available at <http://ecdc.europa.eu/en/publications/Publications/ecdc-tuberculosis-surveillance-monitoring-Europe-2017.pdf>

¹⁰ European Centre for Disease Prevention and Control/WHO Regional Office for Europe. Tuberculosis surveillance and monitoring in Europe 2016, page 80

¹¹ http://ecdc.europa.eu/en/healthtopics/Tuberculosis/epidemiological_data/Documents/2017/ecdc-tb-surveillance-monitoring-eur-2017-profile-romania.pdf

¹² Call for an Inclusive New Financial Allocation for the TB Control Programme in Romania, The Romanian Country Coordination Mechanism addressing the Thirty Sixth Meeting of the Global Fund Board (annex 3)

¹³ <http://www.raa.ro/wp-content/uploads/2016/05/1.2.-WHO-report-Legal-Impediments-in-centralised-TB-drugs-procurement-in-Romania.pdf>

¹⁴ Romanian Parliament, Chamber of Deputies, Draft Law on the measures of prevention and control the tuberculosis, PI-x nr. 470/2016, http://www.cdep.ro/pls/proiecte/upl_pck2015.proiect?idp=15977 and the call for adopting the law: <https://campaniamea.de-clic.ro/petitions/deputati-votati-legea-tuberculozei>

¹⁵ http://www.tbonline.info/media/uploads/documents/who_guidelines.pdf

¹⁶ Report: Out of Step 2015 - TB policies in 24 countries, <https://www.msfaccess.org/content/report-out-step-2015-tb-policies-24-countries>

¹⁷GLC-Europe Monitoring Mission to Romania, May 2 - 8, 2016 , http://www.raa.ro/wp-content/uploads/2016/11/GLC_Mission_Report_Romania_2016_final-1.pdf