Monitoring of human rights of persons in health and social care institutions in Lithuania using the WHO Quality Rights toolkit.

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Brief info about the Lithuanian context regarding health and welfare services and mental health services specifically

The right of the individual to the highest attainable standard of physical and mental health is protected in the UN Convention on the rights of persons with disabilities (CRPD) Art. 25 obliges states the need to take all necessary measures to ensure that a person's disability situations do not prevent them from achieving the best possible health. The state is committed to providing safe and high-quality human rights services to those receiving treatment for mental health problems. This right is protected by the provisions of Paragraph 1 of Article 53 of the Constitution of the Republic of Lithuania, which establishes that the state takes care of people's health and guarantees medical assistance and services in case of illness. The law establishes the procedure for providing free medical assistance to citizens in state medical institutions.

Even though the health status of the Lithuanian people has improved over the past ten years, it remains well below most EU countries, and the difference between men and women is large. Health expenditure in Lithuania in 2019 is comparatively low, at just under EUR 1 900. It has grown slightly faster than the EU average over the past years, but when measuring as a share of GDP, health spending in Lithuania remained quite low, at 7.0 %, compared to the EU average of 9.9 % (OECD, 2021).

Yet, part of the health budget allocated to mental health is even decreasing from 5,1 percent in 2015 to 4,6 percent in 2019 in Lithuania. The country spends less for mental health care as a proportion of governments health expenditures then the OECD average 6,6 percent (OECD, 2021).

The updated Lithuanian Health Strategy for 2014–2025 seeks to make the Lithuanian residents healthier and live longer, improve the residents' health, and reduce health disparities by 2025. The four goals of the Health Strategy are as follows: creation of a safer social environment, reduction of health disparities and social exclusion; creation of a health-friendly physical working and living environment; shaping healthy lifestyle and its culture; achievement of a quality and effective health care, focused on the needs of the residents.

The Ministry of Health is responsible for formulating health policy and regulations; monitoring population health; licensing providers and health professionals; governing the NHIF; and managing the network of subordinated institutions, including some providers.

The Lithuanian health system is organised around a single payer – the National Health Insurance Fund (NHIF) – which purchases services on behalf of the insured population and aims to cover all residents. In 2020, 99 % of the population were covered by compulsory health insurance (OECD, 2021). People who are employed and self-employed, as well as some other groups (such as farmers, artists, and small business owners) make mandatory contributions. The non-working population is insured by the state.
In 2019, only 46 % of the Lithuanian population reported being in good health – the lowest rate in the EU. Very high suicide rates, usage of alcohol and other psychoactive substances reflect aspects of poor mental health among the Lithuanian population. Mental and morbidity behavioural disorders constitute 11.2 percent population (313,664 persons).

According to the WHO Global health estimates (2019) 11,7 percent of population with mental and morbidity behavioural disorders affecting DALYs (disability- adjusted life years) due to the disability. In 2019, the Mental Health Act (Law on Mental health care, 2019) was amended to improve regulation of mental health care provision. The changes sought to improve access to mental health services at the community and primary care levels. The law establishes a comprehensive (team-based) model for providing personal mental health care services, a priority of non-medical treatment and offering closer assistance without disrupting a person's daily routine.

The implementation of the Lithuanian mental health care reform included reducing the number of inpatient psychiatric beds and establishing municipal mental health centres. In 2021, in Lithuania there were 107 municipal mental health centres employing expert teams: psychiatrists, children's and adolescent psychiatrists, medical psychologists, social workers and mental health nurses. Providing mental health outpatient assistance on the primary level enables to make mental health assistance more easily available to the residents and improves its quality.

According to information from the Ministry of Health, funding from the State Health Insurance Fund (2019) was divided as following: 52,2 mln. (68%) Euro for inpatient treatment in the hospitals, 7,1 mln Euro for outpatient mental health services and 17,9 mln Euro for primary mental health care services. More than 50% of all specialized services (excluding primary care) are inpatient services. It demonstrates the imbalance of available services and does not correspond human rights-based approach to mental health, which is based on community services.

The new Mental Health Care Law seeks to strengthen the protection of human rights through increased transparency and objectivity in the process of involuntary hospitalization of people with mental and behavioural disorders. The Description of Involuntary Hospitalization and Involuntary Treatment of Patients with Mental and Behavioural Disorders is detailing the procedures for involuntary hospitalization and involuntary treatment, and the conditions under which involuntary hospitalization or involuntary treatment is possible, patient information and consent procedures, and other relevant aspects. The Description specifies the procedures and forms to be used for involuntary hospitalization and involuntary treatment and establishes the procedure for monitoring. Unfortunately, aligning the new provisions of the Mental Health Care Law with the existing provisions in the Civil Code (Civil Code, 2016), involuntary hospitalization and/or involuntary treatment has been even expanded. The envisaged criteria for involuntary hospitalization of a person are determined as real threat to his or her health or life, or the health or life of other persons, or significant damage to the property. Such extension of involuntary hospitalization and treatment is not in line with the provisions of the CRPD.

The system of residential care institutions in Lithuania is an organized, large, and powerful system, that has been formed during the Soviet times and still functions despite criticism for human rights violations and irrational use of financial resources. Currently this is the main form of care for persons with intellectual and/or psychosocial disabilities who are in need of a long-term care (Genienė, Šumskienė, 2016).
According to the data from the Department of Supervision of Social Services under the Ministry of Social Security and Labour, in total there are 196 facilities providing social care services in Lithuania (2021), taking care of 13 300 elderly persons and persons with disabilities Whereas specifically for persons with disabilities long-term social care services were provided in 31 state facilities accommodating more than 6 000 residents at the beginning of 2020 (Ministry of Social affairs and Labour 2021). On average, social care institutions in Lithuania host from 100 to 400 residents, and, as a result, are far from home type services.

The issue of deinstitutionalisation

Deinstitutionalisation processes[1] started still in 2014, yet had been slow in Lithuania. Nevertheless, there are some concerns that too little attention and financing is directed towards the creation of actual independent living schemes. In Lithuania community-based accommodation services for people with mental health problems are extremely limited and primarily consist of group home placements that are available for a fraction of those using residential care. With a plan in progress to build 50 group living homes around the country (10 people living in one setting with the help of staff), which is considered a large proportion in comparison with community-based services promoting independent living, which is promoted and supported by CRPD. Even for these structures, there were numerous acts of resistance from local communities manifested, which indicates lack of systemic preparedness for deinstitutionalisation process and proper tackling stigma and discrimination in the society.

Monitoring of human rights of persons with disabilities in Lithuania

After ratification of the CRPD in 2010, Lithuania has been obliged to strengthen its institutional mechanisms for monitoring of the rights of persons with disabilities. With regards to monitoring of the implementation of human rights of people with disabilities, non-governmental organisations have always been the most active in continues assessments and monitoring being performed, including in social care institutions and/or psychiatric institutions[2]. Human rights monitoring in social care homes and psychiatric hospitals is performed also by Seimas ombudsmen office which since 2014 has function of National preventive mechanism assigned to them by law in the framework of the Optional Protocol to the United Nations Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment by Seimas Ombudsmen Institution[3]. In performing this function, the Seimas ombudsmen regularly visit various places of deprivation of liberty. Such monitoring, with regular visits to places of detention and the presentation of recommendations is effective means of preventing human rights abuses and is an excellent way of improving the conditions of detention.

But due to large number of detention places in Lithuania (about 450), the attention to psychiatric hospitals and social care homes might be limited, especially during the period of lockdown, when closeness of such institutions is even greater.

On July 1, 2019, following the entry into force of the amendments to the Law on Equal Opportunities, the Commission for the Monitoring on the Rights of Persons with Disabilities was established[4] under the Office of the Equal Opportunities Ombudsperson was established aiming at monitoring the implementation of the CRPD.

In 2016, the UN Committee on the Rights of Persons with Disabilities (hereinafter – the Committee) provided recommendations to Lithuania with regards proper implementation of the Convention. Committee recommended "to improve monitoring and inspection of social care homes and psychiatric institutions to prevent violence against and abuse of residents with disabilities"; "ensure that persons deprived of liberty have access to independent complaint mechanisms"; "collect disaggregated data and designate independent authorities to monitor services and facilities" to properly implement art. 16 (Freedom from exploitation, violence and abuse) of CRPD.

1 *National Deinstitutionalisation project website* https://www.pertvarka.lt/

2 *2003-2006 year European Commission project "Prevention of torture. Support and rehabilitation for persons in closed type institutions (prisons, police, psychiatric hospitals and social care institutions) in Latvia, Estonia, Lithuania and Kaliningrad region", Report „Human rights in mental health care in Baltic States", Vilnius, 2006 m.; 2007-2010 year European Commission funded project "Institutional treatment, Human rights and Care assessment" (ITHACA); Rights of persons with disabilities. Human rights implementation overview in Lithuania in 2007, 2008 and 2009-2010, 2011-2012, 2013-2014 reports, prepared by Human rights monitoring institute.*

3 *Seimas Ombudsman office website* https://www.lrski.lt/veiklos-sritys/nacionaline-kankinimu-prevencija-nkp/

4 *Commission for the Monitoring on the Rights of Persons with Disabilities* https://lygybe.lt/lt/naujienos/kontroliere-subure-pirmaja-zmoniu-su-negalia-teisiu-stebesenos-komisija/1127

To ensure the proper implementation of art. 19 (Living independently and being included in the community) of CRPD the Committee recommended to "adopt an adequately funded strategy for deinstitutionalization ensuring a range of community-based services for the social inclusion of persons with disabilities, […] including their right to live independently in the community; […] eliminate excessive waiting time for receiving support services by investing in developing new services and rendering existing services accessible and inclusive and ensure that persons with disabilities have access to sufficient financial resources for independent living and improved access to accessible services in the community"(Unites Nations Committee on the Rights of Persons with Disabilities, 2016). Yet, the number of persons with disabilities in long-term care institutions are not decreasing and there is a constant waiting list for referral to social care homes. According to data of January 30, 2019 in total 428 people were waiting in line to enter care institutions (Grigaitė, Jurevičiūtė, 2019). A significant part of people with disabilities living in institutional care are relatively self-sufficient and could live in community with necessary support. Meanwhile the community services as alternative to inpatient care are underdeveloped in terms of both availability, supply, and quality. In the absence of functioning network of community-based care services, an individual with limited independence and no sufficient services usually has no choice but to stay in an inpatient care facility. (Pūras, Šumskienė at al, 2013).

All the above-mentioned situation highlight the need for constant independent monitoring of mental health care institutions and human rights of persons receiving services there as they continue to be the monopoly of provision of long-term care for persons with disabilities in Lithuania. Since "some of the worst human rights violations and discrimination experienced by people with mental disabilities, intellectual disabilities, and substance abuse problems is in health-care settings. … quality of care in both inpatient and outpatient facilities is poor or even harmful and can actively hinder recovery. The treatment provided is often intended to keep people and their conditions 'under control' rather than to enhance their autonomy and improve their quality of life" (World Health Organization, 2012).

WHO QualityRights toolkit

WHO QualityRights toolkit was developed based on the United Nations Convention on the Rights of Persons with Disabilities (CRPD) as the basis for human rights standards that must be respected, protected and fulfilled in facilities.

Disability organisations[5] were active with regards to implementation of the CRPD, as well as with development, piloting and using the WHO QualityRights toolkit from the very beginning. Lithuanian national expert team was organised[6] for participating in the WHO project for adults with psychosocial and intellectual disabilities living in institutions in the European Region[7]. It was active since 2017, when QualityRights assessments were conducted in 75 facilities across 24 WHO Member States and also Kosovo. A report was published following this project: Mental health, human rights and standards of care. Assessment of the quality of institutional care for adults with psychosocial and intellectual disabilities in the WHO European Region (World Health Organisation, 2018).

5 *Association "Lithuanian disability forum", NGO "Mental health perspectives", etc.*

6 *Nijolė Goštautaitė Midttun, Ugnė Grigaitė, Dovilė Juodkaitė and Karilė Levickaitė*

7 *At the request of Member States, the WHO Regional Office for Europe undertook an assessment of current practices and shortcomings in institutions that provide long-term care for adults with psychosocial and intellectual disabilities. In phase 1, all Member States in the European Region were invited by the Regional Director to complete a survey of institutions that provide long-term care for adults with psychosocial and intellectual disabilities. The survey was administered in the 31 participating countries and Kosovo. In this phase 2 of the project, the quality of care and protection of human rights in selected institutions in over 20 countries in the WHO European Region were rated with the WHO QualityRights toolkit.*

Quality Rights in Lithuania

As part of the WHO project three social care homes were selected in Lithuania for assessment in 2017/2018. The selection of social care homes was based on the number of residents (the largest social care home was included), the territorial (big city, or suburban territory), state owned or municipal level social care home.

Main results of the monitoring of social care homes in Lithuania reveal that there is lack of knowledge and understanding of mental health and human rights protection among the administration and staff of facilities. There is a lack of ways to personalise care and recovery, and lack of rehabilitation (and even employment) activities in most of the evaluated institutions. There is also lack of legal assistance or representation for persons living in long-term care institutions. Due to the lack of alternative services in the community, there is quite big number of persons in institutions that could be living in community with relevant support. After the assessment of three social care homes general recommendations were presented to the Ministry of Social security and labour, as well as targeted recommendations were discussed with all three social care homes. General recommendations revealing overall situation of evaluated institutions, highlight that staff training and exchange of good practice are needed, especially in the areas of human rights, recovery, and independent living.

There this a need for additional social services for people with mental disabilities to emerge for better integration in the community, including cooperation with municipal social services. Increased efforts to help service users understand their rights, to help contact legal services whenever they want and without censorship.

Isolation and restraint must not be used, personnel must be trained in appropriate de-escalation techniques and procedures. More attention needs to be paid to professional and employment activities, especially given the large number of people working informally.

Phase 3 of the project was foreseen for introducing quality improvement measures within the evaluated institutions. In 2018/2019 with the support of national expert team members targeted trainings and development of plans for implementation of recommendations provided were introduced in two social care homes in Lithuania.

After the participation within WHO Regional office project, national experts were very active in promoting the WHO QualityRights toolkit to be used on national level for monitoring of institutions for persons with intellectual and mental disabilities. NGO representative experts were actively suggesting both for Ministry of Social security and labour and Ministry of Health care to include the specific measures for promoting human rights approach in social care and mental health care systems, supporting deinstitutionalisation process and mental health care reforms.

By the current leadership of Ministry of Health care national experts[8] were invited to conduct the assessment of two psychiatric hospitals in 2021. The full assessment procedure following the QualityRights toolkit principals and stages was performed, conclusions and recommendations presented to all the stakeholders. In 2022 the continuation of the monitoring exercise and assessment of Lithuanian psychiatric institutions is planned further, as well as planning of quality improvement measures within the evaluated institutions.

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To conclude, there is a political will to strengthen human rights-based approach within mental health care services in Lithuania. For the upcoming years (till 2030), there are systemic solutions proposed to be implemented, that include: Recovery paradigm implementation; strengthening of person-centered and follow-up care services; testing and implementation of quality assessment tools; assessment of human rights principles and methodological assistance to institutions; Psychological adaptation and systematization of assessment tools. WHO QualityRights assessment toolkit is proposed to be used for evaluation of quality of mental health services and human rights standards in Lithuania in mental health institutions.
human rights faced a considerable backlash.

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