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**Human Rights Conditions and Quality of Care in ‘Independent Living Homes’ for Adults, who have Intellectual and/or Psychosocial Disabilities, in Vilnius:  
Analysis of Good Practice Examples, Systemic Challenges and Recommendations for the Future**

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Sincerely, Ugnė Grigaitė  
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## **Abstract (English)**

*Within the broader context of related major paradigm shift taking place across the world, Lithuania is currently undergoing its own deinstitutionalization of social care and mental health services. The abovementioned paradigm shift from the bio-medical towards a more comprehensive bio-psychosocial model has been brought about internationally with the adoption of the UN Convention on the Rights of Persons with Disabilities over a decade ago. Lithuania ratified this human rights treaty in 2010 and over the following years started implementing its provisions and principles in national legislation, policies, plans, programmes and practices. As a major part of the deinstitutionalization process, new community-based services, such as two ‘Independent Living Homes’ in Vilnius, were established. It has been planned that these new services will eventually replace the long-term residential care, which is presently predominant and rooted in institutional culture. The main questions addressed by this study examine the actual effectiveness of such new services, the quality of care provided in them and the level of compliance with international human rights standards on the ground. This thesis explores the critical need to ensure that the human rights based approach is at the core of any new developments and delivery of community-based services, and of deinstitutionalization in general. Based on the comprehensive literature review, as well as the unique empirical research findings herein, obtained by implementing the WHO QualityRights Assessment in two Municipal ‘Independent Living Homes’ in the capital city of Lithuania, this study points to both the good practices, as well as the gaps in these services’ provision. Additionally, it discovers the deeply-rooted systemic issues that surround and restrict the current and potentially the future development, effective delivery and improvement of community-based services for the most vulnerable individuals in our society. This thesis suggests that there is a great need to critically review the current direction of the deinstitutionalization in Lithuania. It is crucial to ensure its compliance with the international human rights standards and evidence-based best practices. At the same time it is important to truly involve persons, who have mental health problems, intellectual and/or psychosocial disabilities, as well as their families, and representing organizations, in all stages of such a review and also of planning for the future of community-based support and services in the country.*

### **Key words**

*Human rights, mental health, psychosocial disability, intellectual disability, UN CRPD, WHO QualityRights<sup>1</sup>, social services, independent living, deinstitutionalization, Lithuania*

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<sup>1</sup> WHO QualityRights tool kit to assess and improve quality and human rights in mental health and social care facilities. Geneva, World Health Organization, 2012.

## **Resumo (Portuguese)**

*No contexto da mudança de paradigma que tem ocorrido no mundo, a Lituânia atualmente está a realizar o seu próprio processo de desinstitucionalização dos serviços de cuidados sociais e de saúde mental. A mudança de paradigma mencionada, de um modelo bio-médico para um modelo de cuidados bio-psicossociais, tem lugar no cenário internacional, com a adoção, há mais de uma década, da Convenção da Organização das Nações Unidas sobre os Direitos das Pessoas com Deficiência. A Lituânia ratificou esse tratado de direitos humanos em 2010 e, ao longo dos anos seguintes, começou a implementar as suas disposições e princípios na legislação nacional, e nas políticas, planos, programas e práticas. Como parte importante do processo de desinstitucionalização, foram estabelecidos novos serviços comunitários, tais como as duas "Independent Living Homes" (Casas de Vida Independente) em Vilnius. Em relação a esses serviços, o planeamento é de que esse irão substituir os cuidados de caráter asilar de longo prazo, que são atualmente predominantemente e enraizados na cultura institucional. As principais questões abordadas nesta tese examinam a eficácia real de tais novos serviços, a qualidade dos cuidados neles prestados e o nível de conformidade dos serviços com os padrões internacionais de direitos humanos. Esta tese explora a necessidade crítica de garantir que uma abordagem baseada nos direitos humanos seja o cerne de quaisquer novas práticas e ações de serviços baseados na comunidade, e do processo de desinstitucionalização como um todo. A partir da revisão abrangente de literatura, bem como dos resultados empíricos dessa pesquisa obtidos por meio da aplicação do kit de ferramentas Direito é Qualidade da OMS (WHO QualityRights) em dois serviços municipais do tipo "Independent Living Homes" localizados na capital de Lituânia, os resultados desta tese indicam as boas práticas realizadas, bem como as lacunas na prática desses serviços. Ainda, revela as problemáticas sistémicas profundamente enraizadas que estão presentes e criam restrições, considerando os serviços baseados na comunidade voltados para os sujeitos mais vulneráveis de nossa sociedade, para o atual e potencialmente futuro desenvolvimento, prática efetiva e melhora desses serviços. Esta tese sugere que há necessidade de revisar criticamente a direção atual dos processos relacionados com a desinstitucionalização na Lituânia. É crucial assegurar o cumprimento dos padrões internacionais de direitos humanos e das boas práticas baseadas em evidências. Ao mesmo tempo, é importante envolver, de fato, as pessoas, que apresentam problemáticas de saúde mental, incapacidades intelectuais e / ou psicossociais, bem como as suas famílias e organizações representativas, em todas as etapas de tal revisão e também de planeamento para o futuro de serviços baseados na comunidade no país.*

### **Palavras-chaves**

*Direitos humanos, saúde mental, incapacidade psicossocial, incapacidade intelectual, CDPD, WHO QualityRights<sup>2</sup>/ OMS Direito é Qualidade, serviços sociais, vida independente, desinstitucionalização, Lituânia.*

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<sup>2</sup> WHO QualityRights tool kit to assess and improve quality and human rights in mental health and social care facilities. Geneva, World Health Organization, 2012.

## **Abstracto (Spanish)**

*En el contexto más amplio del importante cambio de paradigma que se está produciendo en todo el mundo, Lituania está experimentando actualmente su propia desinstitucionalización de los servicios de atención social y de salud mental. El cambio de paradigma antes mencionado desde el biomédico hacia un modelo bio-psicosocial más amplio se ha logrado a nivel internacional con la adopción de la Convención de las Naciones Unidas sobre los Derechos de las Personas con Discapacidad hace más de una década. Lituania ratificó este tratado de derechos humanos en 2010 y durante los años siguientes comenzó a aplicar sus disposiciones y principios en la legislación, las políticas, los planes, los programas y las prácticas nacionales. Como parte importante del proceso de desinstitucionalización, se establecieron nuevos servicios basados en la comunidad, como dos «Viviendas independientes» en Vilna. Se ha planificado que estos nuevos servicios sustituyan a largo plazo la atención residencial, que actualmente es predominante y está arraigada en la cultura institucional. Las principales cuestiones abordadas en esta tesis examinan la efectividad real de estos nuevos servicios, la calidad de la atención prestada en ellos y el nivel de cumplimiento de las normas internacionales de derechos humanos sobre el terreno. Esta tesis explora la necesidad crítica de garantizar que el enfoque basado en los derechos humanos esté en el centro de todo nuevo desarrollo y prestación de servicios comunitarios y de la desinstitucionalización en general. Basado en la revisión bibliográfica exhaustiva, así como en los hallazgos de investigación empírica únicos obtenidos mediante la implementación de la Evaluación QualityRights de la OMS en dos instalaciones municipales independientes en la capital de Lituania, esta tesis apunta tanto a las buenas prácticas así como las brechas en la provisión de estos servicios. Además, descubre los problemas sistémicos profundamente arraigados que rodean y restringen el desarrollo actual y potencialmente futuro, la entrega efectiva y la mejora de los servicios basados en la comunidad para las personas más vulnerables de nuestra sociedad. Esta tesis sugiere que existe una gran necesidad de revisar críticamente la dirección actual de los procesos relacionados con la desinstitucionalización en Lituania. Es fundamental garantizar su cumplimiento de las normas internacionales de derechos humanos y las mejores prácticas basadas en datos probatorios. Al mismo tiempo, es importante involucrar verdaderamente a las personas que tienen problemas de salud mental, discapacidades intelectuales y / o psicosociales, así como a sus familias y organizaciones representativas, en todas las etapas de dicha revisión y también de la planificación para el futuro de apoyo y servicios comunitarios en el país.*

### **Palabras clave**

*Derechos humanos, salud mental, discapacidad psicosocial, discapacidad intelectual, UNCRPD, derechos de calidad de la OMS<sup>3</sup>, servicios sociales, vida independiente, desinstitucionalización, Lituania*

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<sup>3</sup> Herramientas de Derechos de Calidad de la OMS para evaluar y mejorar la calidad y los derechos humanos, en salud mental y centros de atención social. Ginebra, Organización Mundial de la Salud, 2012.

## **Santrauka (Lithuanian)**

*Platesniame kontekste, susijusiame su šiuo metu vykstančia paradigmos kaita visame pasaulyje, Lietuva patiria socialinės globos bei psichikos sveikatos priežiūros paslaugų deinstytucionalizaciją. Minėtas paradigmos poslinkis ir perėjimas nuo biomedicininio prie biopsichosocialinio modelio buvo paskatintas tarptautiniu mastu daugiau nei prieš dešimtmetį, kuomet buvo priimta Jungtinių Tautų Neįgaliųjų teisių konvencija. Ši žmogaus teisių sutartis Lietuvoje buvo ratifikuota 2010 metais ir nuo tada šalis įsipareigojo siekti, kad konvencijos nuostatos bei principai būtų įtvirtinti nacionaliniuose teisės aktuose, politikoje, veiksmų planuose, programose bei praktikoje. Kaip viena svarbiausių deinstytucionalizacijos proceso dalių, Lietuvoje pradėtos steigti naujos paslaugos bendruomenėje, tokios kaip, pavyzdžiui, dveji bendruomeninio tipo savarankiško gyvenimo namai Vilniuje. Buvo planuojama, jog minėtos naujosios paslaugos galiausiai pakeistų šiuo metu dominuojančią ir institucinėje kultūroje išsakinijusią ilgalaikę socialinę globą. Pagrindinis šio mokslinio darbo tikslas yra išnagrinėti ar šios naujosios paslaugos yra efektyvios, kokia yra juose teikiama pagalba žmonėms kokybė bei koks yra atitikimo tarptautiniams žmogaus teisių standartams lygis. Šiame darbe pristatomas ir nagrinėjamas kritiškas poreikis užtikrinti, jog bet kokių naujovių plėtra, bendruomeninio tipo paslaugų bei pačios deinstytucionalizacijos bendrai šerdis yra požiūris, grįstas žmogaus teisėmis. Remiantis išsamia literatūros analize bei rezultatais unikalaus empirinio tyrimo, atlikto dviejuose Lietuvos sostinėje veikiančiuose savarankiško gyvenimo namuose, pritaikius Pasaulio sveikatos organizacijos „WHO QualityRights“ metodiką, šiame darbe yra aptariami tokių paslaugų privalumai ir trūkumai. Darbe taip pat atskleidžiamos sisteminės spragos ir problemos, kurios yra giliai išsakinijusios ir tokiu būdu apibrėžia ir apriboja dabartinę bei potencialiai ateities plėtrą efektyvių bendruomeninio pobūdžio paslaugų, skirtų labiausiai pažeidžiamiems mūsų visuomenės nariams. Darbe yra siūloma kritiškai įvertinti ir peržiūrėti dabartinių, su deinstytucionalizacija susijusių procesų kryptį Lietuvoje. Labai svarbu užtikrinti, jog deinstytucionalizacijos procesai atitiktų tarptautinius žmogaus teisių standartus ir remtųsi įrodymais grįsta geriausia praktika. Tuo pačiu visuose šio proceso etapuose bei ateityje planuojant geriau įtvirtinti bendruomeninio pobūdžio paslaugas Lietuvoje, labai svarbu į procesą įtraukti pačius asmenis, turinčius psichikos sveikatos problemų, intelekto sutrikimų, proto ir/ar psichosocialinę negalią, jų artimuosius bei juos atstovaujančias organizacijas.*

### **Raktiniai žodžiai**

*Žmogaus teisės, psichikos sveikata, psichosocialinė negalia, intelekto sutrikimai, proto negalia, Jungtinių Tautų Neįgaliųjų teisių konvencija, „WHO QualityRights“<sup>4</sup> metodika, socialinės paslaugos, savarankiškas gyvenimas, deinstytucionalizacija, Lietuva*

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<sup>4</sup> Pasaulio sveikatos organizacijos „QualityRights“ metodika, paslaugų kokybės ir žmogaus teisių situacijos psichikos sveikatos ir socialinių paslaugų vertinimui ir gerinimui. Pasaulio sveikatos organizacija, Ženeva, 2012.



## Executive summary

### *Purpose*

The aim of this research study was to draw the attention of all key stakeholders, including the academia and government of Lithuania, to the importance of ensuring that the human rights based approach is at the core of any present and future developments of community-based services, and of deinstitutionalization in general. The findings analysed and discussed in this study are based on the *World Health Organization's QualityRights (WHO QR)*<sup>5</sup> assessment of two community-based 'Independent Living Home' facilities for persons, who have intellectual and/or psychosocial disabilities, in Vilnius, Lithuania. It was a unique piece of qualitative research, completed as such for the first time in the country. It also has an applied practical value, as the produced recommendations may immediately be used and implemented in services currently provided in the two assessed facilities, in order to improve quality of life of service users, services' effectiveness and compliance with international human rights standards.

### *Methods*

The overall management and coordination of the *WHO QR Assessment* was undertaken by the Author of this thesis, who also had the responsibility for compiling and coordinating the Assessment Committee. Individuals from different professional and personal backgrounds were represented in the Assessment Committee. The actual fieldwork was undertaken by 9 out of 12 Assessment Committee's members, and took place during the months of June and July 2017. The remaining three members of the Assessment Committee provided their advisory input during the later stages of data analysis and producing of the recommendations. The data was collected by reviewing both facilities' internal documents, conducting observations and carrying out a total of 30 interviews with service users and staff.

### *Results*

**Table 1: Summary of the Results**

Theme	Rating (Home 1)	Rating (Home 2)
<b>Theme 1:</b> The right to an adequate standard of living (Article 28 of the UN CRPD <sup>6</sup> )	Achieved partially (A/P)	Achieved partially (A/P)
<b>Theme 2:</b> The right to enjoyment of the highest attainable standard of physical and mental health (Article 25 of the UN CRPD)	Achieved partially (A/P)	Achieved in full (A/F)
<b>Theme 3:</b> The right to exercise legal capacity and the right to personal liberty and security of person (Articles 12 and 14 of the UN CRPD)	Achieved partially (A/P)	Achieved partially (A/P)

<sup>5</sup> WHO QualityRights tool kit to assess and improve quality and human rights in mental health and social care facilities. Geneva, World Health Organization, 2012.

<sup>6</sup> United Nations Convention on the Rights of Persons with Disabilities.

<b>Theme 4:</b> Freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse (Articles 15 and 16 of the UN CRPD)	Achieved partially (A/P)	Achieved partially (A/P)
<b>Theme 5:</b> The right to live independently and be included in the community (Article 19 of the UN CRPD)	Achievement initiated (A/I)	Achievement initiated (A/I)

## ***Discussion***

In its current state, the two studied ‘Independent Living Homes’ were assessed to have some positive features and practices; however, improvements are needed in all five thematic areas explored by this study. The right to an adequate standard of living was discovered to be ensured mostly on the physical and material levels; however, gaps were identified in practice related to the lack of human rights based approach and recovery oriented models of support provided in the two facilities. Investment in professional development of staff is lacking, which creates obstacles for a more effective services’ provision. The right to the highest attainable standard of *physical health* is mostly ensured in both facilities, however, that of *mental health* is more complicated, neglected and left behind. None of the service users are deprived of their legal capacity; however, neither supported decision making nor use of advance directives are employed in either of the two facilities. In the most severe cases, especially in cases of fights taking place amongst service users, the staff of both facilities call the police or ambulance and the person receives all the necessary treatment. However, none of the staff are trained on alternatives for seclusion or restraint, nor on de-escalation techniques that would help to avoid any harm being done to both service users and staff themselves. The right to live in the community is initiated in both facilities; however, they still display a lot of features of institutional culture and staff demonstrate bio-medical model based attitudes towards mental health.

## ***Conclusion and recommendations***

In the broader systemic context of Lithuania’s obligation to implement the principles and direction of the UN CRPD in its national legislation, policy, action plans, programmes and practices, this study of quality of care and human rights conditions in two Municipal ‘Independent Living Homes’ in Vilnius has conclusions on two parallel levels. One is the facility-based level and the other one is system-based. Both the good practices, as well as gaps in these services’ provision have been identified by the study. Moreover, the study has discovered deeply-rooted systemic issues that surround and restrict the current and potentially the future development, effective delivery and improvement of community-based services for persons, who have mental health problems, intellectual and/or psychosocial disabilities. The results of this study suggest that there is a great need to critically review the current direction of the deinstitutionalization in Lithuania, in order to ensure its compliance with the international human rights standards and evidence-based best practices.

## Introduction

For decades people who have mental health problems, intellectual and/or psychosocial disabilities have been confined in large segregated social care and/or psychiatric institutions in most countries across the world (Wing and Brown, 1970; Grob, 1991; Desjarlais et al, 1995; Thornicroft and Tansella, 1999; Thornicroft and Tansella, 2004). An institution is any residential care setting where: a) service users are isolated from the broader community, society and/or compelled to live together; b) they do not have sufficient control over their own lives and decisions which affect them; and c) the requirements and interests of the institution itself takes precedence over the service users' individual needs (European Expert Group on the Transition from Institutional to Community-based Care, 2012). Despite some ongoing developments in the field, this is still the main form of social care and mental health services in Lithuania up to this day. According to the latest data provided by the Ministry of Social Security and Labour, over 6,000 adults and children live in more than 40 social care institutions in Lithuania (total population of the country being approximately just over 2,8 million in 2017). Additionally, up to 200 persons are consistently in queues at any given time waiting to be admitted. The system of social care and psychiatric institutions in Lithuania, like in most of the other former Soviet republics, is one of the most disturbing phenomena, where human rights of individuals tend to be violated on a daily and systemic basis (The Seimas Ombudsman's Office of the Republic of Lithuania, 2016; United Nations High Commissioner for Human Rights, 2017). Institutional culture thrives in such a segregated, out-dated and human rights violating mental health care system, which perpetuates stigma and discrimination not only within an institution itself but in wider society as well (Grigaite, 2017).

It has been shown by multiple epidemiological studies that the availability and accessibility of segregated specialist treatment services is far from enough to meet the existing demand for treatment, care and support, due to the very high prevalence of mental health problems in any population (Grigaite, 2017). Studies have consistently evidenced that regardless of a country where they live, individuals in community-based services have better overall outcomes, when compared with institutional care. The better outcomes are such as, for example: a) greater accessibility to care, protection of human rights, prevention of stigma (Thornicroft and Tansella, 2003); and b) greater user satisfaction (Thornicroft and Tansella, 2003; Killaspy, 2007). This is also the main focus of Article 19 "Living independently and being included in the community" of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD).

13<sup>th</sup> December 2006 saw the adoption of the UN CRPD by the United Nations General Assembly. None of 'new' human rights were created by this international treaty, however, it has put a clear obligation on the countries, which ratify it, to fully apply and implement both in legislation and in practice the principles of fundamental human rights in the case of people who have disabilities. The importance and uniqueness of this Convention was proven immediately by the fact that it was signed by 82 countries on the very first day of its adoption – this is the highest number of signatures collected on the very first day, higher than what any

other international treaty that had preceded it ever reached. The UN CRPD marks a major shift in attitudes towards people who have disabilities: it emphasizes the bio-psychosocial approach over the strictly bio-medical approach that had been predominant for decades before. Also it recognizes persons with disabilities not merely as ‘objects’ of care and treatment, but rather as fully-fledged right holders and citizens, who are capable to make independent choices and own decisions about all matters that affect their lives. The Convention defines persons with disabilities as those “*who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others*”. Still it is important to note that there is no ‘exhaustive definition’ of disability, which is described by various professionals and persons, who have disabilities themselves, as an ‘*evolving concept*’ (WHO, 2011).

The UN CRPD was ratified by the Lithuanian government in 2010 as a legally binding international human rights treaty. One of the key articles in this Convention is Article 19 “Living independently and being included in the community”, which sets-out standards and principles for full social inclusion, respect for dignity, personal choice and control, and independent living for all people. Moreover, it provides for an obligation of the states to ensure not only opportunities for individual choice and control related to independent living, but also to foster the needed support and availability of community-based services (UN High Commissioner for Human Rights, 2014). Following the ratification of the UN CRPD, a number of legislative and policy developments were initiated in order to make Lithuanian laws and practices more compliant with the international human rights standards and principles. Amongst these changes was the adoption of the Action Plan (2014-2020) for the Transition from Institutional Care to Community-Based Services for Persons with Disabilities and Children Left without Parental Care. Hence, Lithuania has declared its intention to move away from institutional models of care for persons, who have mental health problems, psychosocial and/or intellectual disabilities, and instead to build a new network of community-based services. One of the most important aspects of following this though is ensuring that the human rights based approach is at the core of this soon to be a newly developed system of care and support services provided to one of the most vulnerable and marginalized yet largest minority groups in our society (Patel and Prince, 2010).

In light of the local context briefly outlined above, two Municipal community-based ‘Independent Living Homes’ were established on the outskirts of Vilnius, the capital city of Lithuania, in 2013. This was one of the very first attempts at establishing completely new type of (community-based) services for persons, who have mental health problems, psychosocial and/or intellectual disabilities, in Lithuania. The main idea of establishing and providing this type of service was to move away from the institutional model of care, segregation, social isolation, and to ensure independent living, social inclusion and dignity for all service users.

The findings analysed and discussed in this study are based on a comprehensive literature review and the *World Health Organization QualityRights (WHO QR)*<sup>7</sup> assessment of the two abovementioned ‘Independent Living Homes’ in Vilnius. It was a unique piece of qualitative research, completed as such for the first time in Lithuania. In this thesis, first of all, the literature review, overall and specific objectives of the study will be presented. Then the methodology of the study will be described, followed by a comprehensive presentation of the study results. This will then be followed by a section on discussion and analysis of the results, good practice examples and systemic challenges identified. Finally, the conclusion and recommendations will be drawn and outlined.

## Literature Review

This thesis was preceded by a critical analysis of existing publications, a comprehensive literature review completed by the Author of this thesis throughout the two years period, between 2015 and 2017. It was published as a single-author article in a scientific peer-reviewed Vilnius University STEPP Journal in July 2017, titled *The Deinstitutionalisation of Lithuanian Mental Health Services, in Light of the Evidence-Based Practice and Principles of Global Mental Health* (see Annex 1).

## Overall Objective

The aim of this study is to draw the attention of the government of Lithuania and of all other key stakeholders, including the academia, to the importance of ensuring that the human rights based approach is at the core of any present and future development of community-based services, and of deinstitutionalization in general. The overall objective of this study was to assess the quality of care and services’ adherence to international human rights standards, by implementing an assessment based on the *WHO QualityRights Toolkit* in two Municipal ‘Independent Living Home’ facilities for adults, who have intellectual and/or psychosocial disabilities, in Vilnius. It was completed as a comparison between reality expressed by specific indicators, and criteria expressed by evidence-based standards, as per the *WHO QualityRights Toolkit*.

## Specific Objectives

(1) To assess the quality of care and human rights conditions within two ‘Independent Living’ facilities in Vilnius, according to the five key thematic areas, as per the *WHO QualityRights Toolkit*; (2) To identify and analyse the existing good practice examples within these two facilities; (3) To identify and analyse the main gaps in the quality of care and compliance with human rights standards within the delivery of these relatively new community-based services; (4) To produce recommendations for improvement, as well as for future development of community-based and recovery-oriented services in Lithuania that respect and foster human rights.

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<sup>7</sup> WHO QualityRights tool kit to assess and improve quality and human rights in mental health and social care facilities. Geneva, World Health Organization, 2012.

## Methodology

### *Assessment Committee*

The overall management and coordination of the *WHO QR Assessment* was undertaken by the Author of this thesis. In order to invite them to take part in the assessment, the Author approached each one of the potential Assessment Committee's members individually first. The potential members were identified and selected by the Author on the basis of their previously well-established long term working relationship in the field of human rights and mental health in Lithuania, as well as internationally. A range of different professions, personal and professional backgrounds are represented in the composition of the Assessment Committee. Also a number of the Committee's members are either family members of persons, who have disabilities, or they are themselves current or former users of mental health services.

**Table 2: Composition of the Assessment Committee**

<b>Fieldwork Team:</b>	<ol style="list-style-type: none"><li>1. Prof. Dr. Arūnas Germanavičius, Psychiatrist, Psychiatry Clinic, Department of Medicine, Vilnius University.</li><li>2. Ms. Aurelija Auškalnytė, Psychologist, NGO Mental Health Perspectives; member of the Lithuanian Psychologists' Association.</li><li>3. Ms. Dovilė Juodkaitė, Lawyer, President of Lithuanian Disability Forum.</li><li>4. Ms. Henrika Varnienė, Economist, Director of Lithuanian Disability Forum.</li><li>5. Ms. Indrė Gegeckaitė, Self-Advocate, Trainee Psychologist, Lithuanian Association of Psychology Students.</li><li>6. Ms. Karilė Levickaitė, Psychologist, Director of NGO Mental Health Perspectives; member of the Lithuanian Psychologists' Association.</li><li>7. Ms. Kristina Radžvilaitė, Human Resources Specialist, Lithuanian Autism Association 'Children of the Rain'.</li><li>8. Ms. Monika Nemanytė, Self-Advocate, Project Manager, New Theatre of the Disabled.</li><li>9. Ms. Ugnė Grigaitė, Social Worker, NGO Mental Health Perspectives; NGO Human Rights Monitoring Institute (MSc Student, the Author of this thesis).</li></ol>
<b>Advisory Team:</b>	<ol style="list-style-type: none"><li>10. Prof. Dr. Dainius Pūras, Child Psychiatrist, Psychiatry Clinic, Department of Medicine, Vilnius University; United Nations Special Rapporteur on the Right of everyone to the enjoyment of the highest attainable standard of physical and mental health.</li><li>11. Dr. Eglė Šumskienė, Department of Social Work, Vilnius University; NGO Mental Health Perspectives.</li><li>12. Prof. Dr. Jonas Ruškus, Department of Social Work, Vytautas Magnus University; Expert Member of the United Nations CRPD Committee; member of the <i>Arka</i> Community in Kaunas, Lithuania.</li></ol>

## **Training of the Assessment Committee**

All members of the Assessment Committee are highly qualified, competent and experienced professionals with expertise and a long-term professional and/or personal experience in the field of mental health and human rights. They are some of the most advanced mental health and human rights professionals, and deinstitutionalization advocates in Lithuania. 9 out of 12 are members of the Lithuanian non-governmental organizations and experts' *Coalition Mental Health 2030*.<sup>8</sup> Members of this *Coalition* are united by the modern approach to human rights in mental health, and their mission is to seek openness, transparency and respect for human rights in Lithuanian mental health and social care systems. The *Coalition Mental Health 2030* won a National Equality and Diversity Award for Strengthening Civil Society in March 2017.<sup>9</sup>

Hence, all of the Assessment Committee's members had previously been extendedly trained on topics of human rights and human rights-based approaches, the UN CRPD, global best practice examples of mental health services, deinstitutionalization, community-based services, advocacy, recovery-based approach, human rights monitoring tools, such as ITHACA, and their use, specialist interviewing skills, alternative communication methods, etc.

Having all of the above in mind and due to the summer period, and some of the committee members having travelled abroad, as well as due to the voluntary nature of participation in this *WHO QR* assessment, the initial group session with all of the committee members present at one place was not organized. Nevertheless, the Author and two of the Assessment Committee's members (i.e. Ms. Dovilė Juodkaitė and Ms. Karilė Levickaitė) received the official *WHO QR* training by Dr. Melita Murko (WHO Office in Copenhagen) during the assessment period, as a part of the parallel ongoing *WHO QR* regional project in Lithuania. Additionally, during the month of June 2017, individual training sessions were provided by the Author to each of the Assessment Committee members individually, on the *WHO QR Toolkit*, specialist interviewing skills and any other more specific parts of the assessment, relevant to every individual Assessment Committee's member. Moreover, the Committee members met for a discussion before each of the visits in order to clarify any questions they may have had, to review the interview and observation tools in more depth; and then later following the visits in order to share experiences and observations from conducting the interviews.

## ***Ethical Considerations***

The National Data Protection Inspection was consulted by the Author, and then an official letter sent by the Supervisor of the Author to the Vilnius Municipality's Social Support Division of the Department for Health and Social Affairs. In this official letter compliance

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<sup>8</sup> Coalition Mental Health 2030: [http://perspektyvos.org/en/coalition\\_mental\\_health\\_2030.html](http://perspektyvos.org/en/coalition_mental_health_2030.html)

<sup>9</sup> National Equality and Diversity Awards 2016: <http://www.lygybe.lt/lt/valdovu-rumuose-iteikti-nacionaliniai-lygybes-ir-ivairoves-apdovanojimai-2016>

with both Lithuanian and Portuguese Data Protection Laws was guaranteed for the duration of this research study, as well as for the quality and standards of management of the collected sensitive data following the study's completion.

Additionally, the Bio-Ethics Committee was approached by the Author and clarification received that the Bio-Ethics permit was not needed for this particular assessment-research activities. This was so due to the *social* nature of the study and the fact that no bio-medical hypothesis was being tested by it.<sup>10</sup>

Nevertheless, consent forms have been developed in compliance with the national laws on related ethics, in both the *extended-written* and *Easy-to-Read* formats. All interviewees were fully informed of the purpose of the study in the way and language that they could best understand; confidentiality and anonymous nature of the results reporting were also explained to them; and they were invited to sign the consent forms before any interview took place.

Moreover, confidentiality agreements were developed and signed by all members of the Assessment Committee prior to conducting any research related activities within this study. All individualised interviews took place in private and confidentiality assuring environments, such as the service users' personal bedrooms-studio flats, leisure rooms, or in cases of interviewing staff – in staff rooms. Interviews with service users were conducted in a sensitive manner, using alternative communication methods, such as body language, gestures or *Easy-to-Read* materials, as and when needed. No real difficulties in carrying out interviews with service users were encountered by the Assessment Committee, due to the population of the service users within the two assessed facilities being quite independent individuals, and them having mostly only mild intellectual disabilities or speech impairments, if any.

### ***The Visits***

The preparatory contact with the two assessed facilities started back in 2016: June 2016 for Home 1, and December 2016 for Home 2. The permission to conduct the assessment in both facilities was obtained from the responsible body within the Vilnius City Municipality in 2016. Research Contracts with the directors of both facilities and confidentiality agreements were signed by the Author at the beginning of June 2017. The facilities were open and willing to participate in the assessment, pro-actively asking to receive recommendations, in order to improve the services that they provide.

Moreover, from the very start direct contact was maintained with Dr. Michelle Funk, Coordinator at the *WHO QR* Initiative (Mental health policy and service development, Department of Mental Health and Substance Abuse, WHO Geneva), regarding the completion of this *WHO QR* assessment. Regular updates were provided to her by the Author.

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<sup>10</sup> Law on Ethics of Bio-medical Studies of the Republic of Lithuania (2000): <https://www.e-tar.lt/portal/lt/legalAct/TAR.234B15954C2F/wKarWpLPIL>



**Table 3: Locations and Dates of the Visits**

<b>Name of the Facility (<u>Home 1</u>):</b>	Valakampiai Social Support Facility's Independent Living Home ( <i>BĮ Valakampių socialinių paslaugų namų Savarankiško gyvenimo namai</i> ): <u>A service for persons who primarily have intellectual disabilities.</u>
<b>Country:</b>	Lithuania
<b>City:</b>	Vilnius
<b>Dates of Visits:</b>	27th June 2017 4th July 2017 14th July 2017
<b>Fieldwork Team:</b>	<ol style="list-style-type: none"> <li>1. Prof. Dr. Arūnas Germanavičius, Psychiatrist, Psychiatry Clinic, Department of Medicine, Vilnius University.</li> <li>2. Ms. Aurelija Auškalnytė, Psychologist, NGO Mental Health Perspectives.</li> <li>3. Ms. Henrika Varnienė, Economist, Director of Lithuanian Disability Forum.</li> <li>4. Ms. Indrė Gegeckaitė, Trainee Psychologist, Lithuanian Association of Psychology Students.</li> <li>5. Ms. Karilė Levickaitė, Psychologist, Director of NGO Mental Health Perspectives; member of the Lithuanian Psychologists' Association.</li> <li>6. Ms. Kristina Radžvilaitė, Human Resources Specialist, Lithuanian Autism Association 'Children of the Rain'.</li> <li>7. Ms. Monika Nemanytė, Self-Advocate, Project Manager, New Theatre of the Disabled.</li> <li>8. Ms. Ugnė Grigaitė, Social Worker, NGO Mental Health Perspectives; NGO Human Rights Monitoring Institute (MSc Student, the Author of this thesis).</li> </ol>
<b>Name of the Facility (<u>Home 2</u>):</b>	Vilnius City Social Support Centre's Independent Living Home "My Own Home" ( <i>BĮ Vilniaus miesto socialinės paramos centro Savarankiško gyvenimo namai „Savi namai“</i> ): <u>A service for persons who primarily have psychosocial disabilities.</u>
<b>Country:</b>	Lithuania
<b>City:</b>	Vilnius
<b>Dates of Visits:</b>	4th July 2017 14th July 2017 24th July 2017
<b>Fieldwork Team:</b>	<ol style="list-style-type: none"> <li>1. Ms. Aurelija Auškalnytė, Psychologist, NGO Mental Health Perspectives.</li> <li>2. Ms. Dovilė Juodkaitė, Lawyer, President of Lithuanian Disability Forum.</li> <li>3. Ms. Indrė Gegeckaitė, Trainee Psychologist, Lithuanian Association of Psychology Students.</li> <li>4. Ms. Karilė Levickaitė, Psychologist, Director of NGO Mental Health Perspectives; member of the Lithuanian Psychologists' Association.</li> <li>5. Ms. Kristina Radžvilaitė, Human Resources Specialist, Lithuanian Autism Association 'Children of the Rain'.</li> <li>6. Ms. Monika Nemanytė, Self-Advocate, Project Manager, New Theatre of the Disabled.</li> <li>7. Ms. Ugnė Grigaitė, Social Worker, NGO Mental Health Perspectives; NGO Human Rights Monitoring Institute (MSc Student, the Author of this thesis).</li> </ol>

## ***Review of Documents***

Neither of the two facilities were monitored by an independent monitoring body or team previously. All relevant documents were reviewed in both facilities by the Author, according to the *WHO QR Toolkit's* Review of Documents and Observation Tool. The following is the list of the reviewed documents:

- Facility policies, guidelines, standards and other official directives;
- Administrative records (e.g. number and categories of staff, number, age and gender of service users, admission and discharge records);
- Records of specific events (e.g. complaints, incidents of theft and/or abuse);
- Service users' personal records and files.

*Important to note:* Admission and discharge records were not reviewed as these were unavailable in the two assessed facilities. These documents are a part of the responsible body's, i.e. Vilnius City Municipality's, archives. Additionally, no policies on restraint nor on alternatives to the use of physical force were present in either of the two facilities.

## ***The Observations***

All parts of the two facilities were visited, such as personal bedrooms-studio flats with inbuilt kitchens, eating areas, toilets and bathrooms; common areas, corridors, staircases, lifts; staff rooms; laundrettes; emergency exits; common leisure rooms; etc. Additionally interactions between staff and service users were observed in order to determine whether service users are treated with dignity and respect, whether their privacy is respected, and also in order to observe any power imbalances or expressions of hierarchy.

As per the *WHO QR Toolkit*, observations were made by all of the Assessment Committee's members with all five senses, i.e. by seeing whether washing amenities and toilets are clean; smelling whether the toilets and common areas have a bad odour; feeling whether there is hot running water; hearing whether service users shout or scream, and listening to the tone of voice of staff members.

## ***Sampling, Sample Size***

The number of interviewees was determined in accordance with the guidance provided in the *WHO QR Toolkit*. All interviewees were selected randomly by using the online research randomizer tool ([www.randomizer.org](http://www.randomizer.org)). Additional random selection of interviewees was undertaken, when necessary, by the Assessment Committee, and not the staff, in both homes during the unannounced visits to the facilities.

## *Interviews*

In accordance with the guidance provided in the *WHO QR Toolkit*, it was decided by the Assessment Committee to interview 11 out of 26 service users (~40%), 5 family members, and 6 out of 13 staff members (~50%) in the Home 1; and 11 out of 27 service users (~40%), 5 family members, and 4 out of 8 staff members (50%) in the Home 2.

A total of 11 service users and 5 staff members were interviewed in the Home 1; and 12 service users and 2 staff in the Home 2. Individual interviews on average lasted for an hour, and up to a maximum of 2 hours in a few cases. Locations where the interviews were carried out varied between personal bedrooms-studio flats of service users, common leisure rooms, and staff rooms. Every time complete privacy and confidentiality for the whole duration of the interviews were ensured. Unfortunately, it was not possible to interview any of the family members in either of the homes.

Both male and female service users within a wide age range were interviewed in both homes. More service users than planned were interviewed in the Home 2, since there was not enough staff to be interviewed at the time of one visit, so instead of interviewing staff, the Assessment Committee member interviewed one extra service user.

Both male and female staff members within a wide age range, representing a range of different positions (social workers, social work assistants, duty guards, managers) were interviewed in both homes. However, the Assessment Committee encountered serious difficulties getting to interview staff members in the Home 2. First of all, there is a small number of staff working in Home 2 in general, i.e. 8 persons. Even though the Assessment Committee tried to visit the facility on two different unannounced and then even one announced visit at different times of day, there was always hardly any staff available to be interviewed. This was due to it being summer holidays, staff members being on sickness absence, or those who were present at the facility being too busy with their daily activities supporting the service users. This proved to even be a problem, when specifically arranged with the manager of the facility to conduct staff interviews on the third *announced* visit: when the Assessment Committee team arrived at the facility at the pre-arranged and agreed specific time, there were only two staff members available, who agreed to be interviewed, instead of the planned four.

In the Home 1, 5 out of the planned 6 staff members were interviewed due to some of the staff members not giving their consent for being interviewed, and others being on summer holidays or sickness absence.

Staff members, who were interviewed in both facilities, proved to be responding to all of the questions in a rather tendentious way, with very similar information provided by all of the interviewed staff members across both facilities. Hence, it was decided by the Assessment Committee that there was no need to try and interview even more staff members, as it was

very unlikely that any additional value or important additional information would be collected, if pursuing to interview a higher number of staff members.

Even though the plan was to interview a total of 10 family members across both facilities, this was not achieved. The reason for this is the fact that very few of the service users living in both facilities, and especially in Home 1, have any family members in the first place. For example, only six service users in Home 1 have any relatives. At the time of the visits to the facilities, service users did not have any visitors, who may have been invited to be interviewed randomly and on the spot. Moreover, there are major limitations as to what personal information of the relatives and friends of service users may be revealed by the facilities to third parties, such as the Assessment Committee. Service users themselves did not share any details of their relatives or friends, and did not really suggest anyone else, who may have been interviewed for this purpose. A couple of family members, whose details service users themselves did share with the interviewers did not give their consent and did not agree to participate in the assessment, neither did any of those, who were approached and invited to participate in the study by the facilities' management directly.

*Practical Issues:* No special funding, apart from the Author's personal funds, was available for the completion of this study; hence, all who participated did so completely voluntarily. Nevertheless, the *WHO QR Interview Tool* was translated into Lithuanian by a paid professional translator, and then proof-read by the Author of this thesis, in order to ensure the quality and accurateness of the Lithuanian translation of the Interview Tool. Due to the lack of funds only this limited way of validation of the translated interview tool was possible.

**Table 4: Interviews**

Name and Location of Facility	Total No. of Service Users	Total No. of Staff	Date and time of Visit(s)	Service User Interviews		Staff Interviews		Family, Friends or Carers Interviews	
				Planned	Conducted	Planned	Conducted	Planned	Conducted
<i>Home 1, Vilnius</i>	26	13	27th June 2017; 14:00 – 18:00 (3 team members)	6	6	0	0	5	0
			4th July 2017; 14:00 – 18:00 (8 team members)	3	3	3	3	5	0
			14th July 2017; 13:00 – 17:00 (3 team members)	2	2	2	2	5	0
			<b>Total Interviews:</b>	11	11	6	5	5	0
Name and Location of Facility	Total No. of Service Users	Total No. of Staff	Date and time of Visit(s)	Service User Interviews		Staff Interviews		Family, Friends or Carers Interviews	
				Planned	Conducted	Planned	Conducted	Planned	Conducted
<i>Home 2, Vilnius</i>	27	8	4th July 2017; 14:00 – 18:00 (8 team members)	8	8	4	0	5	0
			14th July 2017; 13:00 – 17:00 (3 team members)	3	3	4	0	5	0
			24th July 2017; 8:30 – 9:45 (3 team members)	0	1	3	2	5	0
			<b>Total Interviews:</b>	11	12	4	2	5	0

**Table 5: Characteristics of Interviewees**

Facility	No. of Female interviewees	No of Male interviewees	Age range of the interviewees	Ethnicity of the interviewees	Range of time lived/worked in the facility
<u>HOME 1 (service users)</u>	6	5	18 - 42 yrs.	Lithuanian Russian Polish Belarus	3,5 yrs. – 4 months.
<u>HOME 1 (staff)</u>	4	1	27 – 54 yrs.	Lithuanian Russian Polish	4 yrs. – 3 months.
<u>HOME 2 (service users)</u>	5	7	22 – 61 yrs.	Lithuanian Russian	3,5 yrs. – 3 yrs.
<u>HOME 2 (staff)</u>	2	0	29 – 45 yrs.	Lithuanian	4 yrs. – 1,5 yrs.

Following each visit, the fieldwork team had brief meetings outside of the facility, sharing their first impressions, experiences and comments from the conducted interviews and observations. Each interview was audio-recorded and then transcribed and fully anonymised by the Assessment Committee members. Following the Author of this thesis reviewing all of the transcriptions and drafting the initial results table with specific comments in it, an online *Google Document* was created as a working file for recording, commenting on and discussing the results for each of the two facilities by the rest of the Assessment Committee’s members (see Table 6: Extended Results Table). In this way the Assessment Committee’s members could share their views on the initial results, discuss their own findings and add to the group assessment of the facilities. It also helped to account for subjectivity in scoring, as all members of the Assessment Committee had to come up with mutually agreed scores: each of the criteria, standards and themes were discussed extensively and various arguments shared, before the final scores were determined. The overall management of the process and technical finalization of the results table was a responsibility of the Author.

The final Assessment Committee’s face-to-face group discussion and analysis of the results took place on 29<sup>th</sup> August 2017 at the Author’s workplace (NGO Mental Health Perspectives) in Vilnius. Most of the Committee’s members, both the Fieldwork Team and Advisory Team, were present (8 out of 12). The main focus of the final meeting and group discussion was put on the *WHO QR Theme No. 5* ‘The Right to Live Independently and being Included in the Community’ (Art. 19 of the UN CRPD), and on agreeing on the final results, conclusions and recommendations that were to be drawn. Those Committee members, who were unable to participate in this meeting in person, provided their comments and input electronically by using the online *Google Documents Tool*, as well as via regular email, Skype and/or telephone communication with the Author.

## Results

The scoring for each of the criteria, standards and themes was completed in accordance with the *WHO Quality Rights Toolkit*, with the scoring definitions as follows:

- **A/F – Achieved fully** – There is evidence that the criterion, standard or theme has been fully realized.
- **A/P – Achieved partially** – There is evidence that the criterion, standard or theme has been realized but *SOME* improvement is necessary.
- **A/I – Achievement initiated** – There is evidence of steps towards fulfilling the criterion, standard or theme but *SIGNIFICANT* improvement is necessary.
- **N/I – Not initiated** – There is no evidence of fulfilling the criterion, standard or theme.
- **N/A – Not applicable** – The specific criterion, standard or theme does not apply to the facility in question.

Colour codes in the Extended Results Table:

- **Yellow** = Theme
- **Blue** = Standard
- **White** = Criterion

Facility codes in the Extended Results Table:

- Home 1 = **H1**
- Home 2 = **H2**

**Table 6: Extended Results Table**

	<b>Theme/ Standard/ Criteria</b>	<b>Result</b>	<b>Comments</b>
<b>1.</b>	<b>The right to an adequate standard of living (Article 28 Of the CRPD)</b>	H1: A/P	
		H2: A/P	
<b>1.1</b>	<b>The building is in good physical condition.</b>	H1: A/P	
		H2: A/P	
<b>1.1.1</b>	The building is in a good state of repair (e.g. windows are not broken, paint is not peeling from the walls).	H1: A/P	<p>The now over 30 years old building was renovated back in 2013, before the facility opened.</p> <p>However, the paint is peeling from the walls in a number of places within the facility; one communal part of the building has no heating and is very damp.</p> <p>Service users pointed out the imperfectness of the state of repair.</p> <p>Service users do not even think they <i>could</i> complain about the state of repair and get it fixed.</p>
		H2: A/P	<p>The now over 30 years old building was renovated back in 2013, before the facility opened.</p> <p>However, the paint is peeling from the walls, and especially in the basement, where the laundrette and leisure room are located, it is especially damp and mouldy.</p> <p>Service users reported that the building has been renovated but mostly from the outside; inside the plumbing system is old and tends to clog-up; hence, it often needs to be repaired.</p> <p>Service users also do not think that there can be an opportunity to fix the problems within the building when they notice them, or that them noticing such problems even matters.</p>



<b>1.1.2</b>	The building is accessible for people with physical disabilities.	H1: A/I	There is an outdoor lift (which brings you up to the abovementioned damp and unheated communal space and not at the main entrance) and a stair-lift, which has been reported to be ‘unreliable’. Only two rooms on the ground floor have accessible bathrooms, and are accessible for persons with physical/mobility disabilities to live in. The emergency exit is completely inaccessible.
		H2: A/I	There is a stair-lift and two accessible bedrooms on the ground floor. However, the rest of the building, the downstairs laundrette and leisure room area is completely inaccessible.
<b>1.1.3</b>	The building's lighting (artificial and natural), heating and ventilation provide a comfortable living environment.	H1: A/P	Some problems with the ventilation systems in the bedrooms-studio flats have been reported by the service users. The heating and lighting in the facility is adequate.
		H2: A/I	It was observed during the visits that all of the corridors are very dark. Many service users reported ventilation problems in their bedrooms-studio flats. Heating has been reported to be adequate.
<b>1.1.4</b>	Measures are in place to protect people against injury through fire.	H1: A/I	Service users could not tell what exact procedures and steps should be followed in case of a fire. Staff reported that they had been trained, however, service users could not share the same. The emergency exit is not at all wheelchair accessible.
		H2: A/I	Service users have heard something about safety measures in case of a fire but don't have a clear knowledge of the related procedures. Some service users have no idea at all where the emergency exit is located at.
<b>1.2</b>	<b>The sleeping conditions of service users are comfortable and allow sufficient privacy.</b>	H1: A/P	
		H2: A/P	

<b>1.2.1</b>	The sleeping quarters provide sufficient living space per service user and are not overcrowded.	H1: A/P	People live in bedrooms-studio flats in twos or threes. Some service users have reported that they do not have enough living space, especially they lack space where to keep their belongings. In cases where service users have more personal belongings (e.g. a fridge, TV, microwave, etc.) and/or the belongings of their child raised there, the living space becomes very limited. Also service users reported that they were not given an opportunity to choose a friend, who they would be sharing their bedroom-studio flat with; only staff had this opportunity.
		H2: A/P	Some service users have their own single bedrooms-studio flats, others have to share theirs with one other person. Some people have reported a lack of space for keeping personal belongings.
<b>1.2.2</b>	Men and women as well as children and older persons have separate sleeping quarters.	H1: A/F	People are allowed to live as couples and/or families; the oldest person in the building is 45 years of age; mothers live in bedrooms-studio flats together with their children; otherwise men share their bedrooms-studio flats with men, and women share theirs with women.
		H2: A/F	Some of the bedrooms-studio flats are occupied by couples, families with children, some are single resident ones, others are shared between two persons – either two women, or two men.
<b>1.2.3</b>	Service users are free to choose when to get up and when to go to bed.	H1: A/F	There is no common schedule or rules to determine when service users are to go to bed or get up in the morning. The facility promotes ‘independent living’ in this sense and encourages service users to have their own timetable and day-to-day routine, in accordance with their own individual wishes and needs.
		H2: A/F	There is no common schedule or rules to determine when service users are to go to bed or get up in the morning. The facility promotes ‘independent living’ in this sense and encourages service users to have their own timetable and day-to-day routine, in accordance with their own individual wishes and needs.

1.2.4	The sleeping quarters allow for the privacy of service users.	H1: A/P	All bedrooms-studio flats are shared between either two or three persons – the space is all shared. If a person wants to get changed in privacy, they have to do that in the bathroom attached to each flat. If a person wants to have guests in his/her bedroom, they may have to ask the other resident to leave the flat for a while; or they may have to go to the only shared space in the building – the ‘leisure room’; or outside of the building.
		H2: A/P	The walls are thin, and service users have reported that they can hear it quite clearly, if someone is talking in the corridor outside their bedroom door, hence, the building is not very well sound insulated, which in its turn negatively affects the privacy situation of service users.
1.2.5	Sufficient numbers of clean blankets and bedding are available to service users.	H1: A/F	Service users buy their own bedding and blankets.
		H2: A/F	The bedding is not provided by the facility, service users have to buy their own bedding and blankets.
1.2.6	Service users can keep personal belongings and have adequate lockable space to store them.	H1: A/P	Service users lack space where to lock away their most precious belongings in their apartment itself. There is a lockable common room in the building next door to the facility, which is a short-term care facility; some of the service users keep their belongings in this room. Also they may ask staff to keep some of their most precious things in the safe, located in the lockable staff room.
		H2: A/P	Bedrooms are lockable but the only lockable cupboard/safe is in the staff room, where service users may keep their more precious personal belongings locked away.
1.3	<b>The facility meets hygiene and sanitary requirements.</b>	H1: A/F	
		H2: A/F	
1.3.1	The bathing and toilet facilities are clean and working properly.	H1: A/F	Service users have <i>en-suite</i> bathrooms and toilet facilities in their apartments. They clean and tidy them up themselves, and they are only clean as much or little as they are looked after by each individual person.

		H2: A/F	Service users have <i>en-suite</i> bathrooms and toilet facilities in their apartments. In case of any issue arising with these facilities service users have to take care of fixing them themselves with using their own finances. That means some things can be broken and remain unfixed for a while. Although according to one service user, when there were some issues with clogged-up plumbing, the facility covered the repair costs.
1.3.2	The bathing and toilet facilities allow privacy, and there are separate facilities for men and women.	H1: A/F	All service users have <i>en-suite</i> bathrooms and toilet facilities in their apartments.
		H2: A/F	All service users have <i>en-suite</i> bathrooms and toilet facilities in their apartments.
1.3.3	Service users have regular access to bathing and toilet facilities.	H1: A/F	All service users have <i>en-suite</i> bathrooms and toilet facilities in their apartments.
		H2: A/F	All service users have <i>en-suite</i> bathrooms and toilet facilities in their apartments.
1.3.4	The bathing and toileting needs of service users who are bedridden or who have impaired mobility or other physical disabilities are accommodated.	H1: N/I	There is not a single service user in the facility at the moment, who is bedridden or has mobility or other physical disabilities. However, there are only two bedrooms on the ground floor, where such people's needs <i>could</i> be accommodated.
		H2: N/I	There is not a single service user in the facility at the moment, who is bedridden or has mobility or other physical disabilities. However, there are only two bedrooms on the ground floor, where such people's needs <i>could</i> be accommodated.
1.4	<b>Service users are given food, safe drinking-water and clothing that meet their needs and preferences.</b>	H1: A/P	
		H2: A/P	
1.4.1	Food and safe drinking-water are available in sufficient quantities, are of good quality and meet with the service user's cultural preferences and physical health requirements.	H1: A/F	Service users are supported to make shopping lists, shop for their own food and drinking-water, according to their individual needs, and budget restrictions.
		H2: A/F	Service users buy food themselves and the ones who are identified by the staff as struggling to manage their finances completely independently are helped in this task: they are offered advice on what foods to buy and in what quantities. The facility also gets charity food products from the Food Bank for those service users,

			who live on the smallest budgets and do not have enough income to cover their basic nutritional needs.
1.4.2	Food is prepared and served under satisfactory conditions, and eating areas are culturally appropriate and reflect the eating arrangements in the community.	H1: A/F	Service users have personal kitchens in their apartments and cook food themselves. They do get support, assistance and help with cooking from staff, if they need it.
		H2: A/F	Service users have personal kitchens in their apartments and cook food themselves. They do get support, assistance and help with cooking from staff, if they need it. There are also regular cooking classes that service users may attend in the day centre that is a part of the same building as the Independent Living Facility.
1.4.3	Service users can wear their own clothing and shoes (day wear and night wear).	H1: A/F	Service users buy their own clothes, according to their personal wishes and according to individual budget restrictions.
		H2: A/F	Service users buy their own clothes, according to their personal wishes and according to individual budget restrictions. The facility does support those, who struggle with very limited budgets, to get clothes from charity too.
1.4.4	When service users do not have their own clothing, good-quality clothing is provided that meets the person's cultural preferences and is suitable for the climate.	H1: A/I	Staff reported that no clothing is provided by the facility, however, in the past charity clothing was given to service users in need, by both the staff members themselves, and by external supporters.
		H2: A/I	Service users stated during the interviews that no clothing is provided by the facility. However, the staff reported that charities are approached if there is a need and service users did get clothing this way in the past.
1.5	<b>Service users can communicate freely, and their right to privacy is respected.</b>	H1: A/F	
		H2: A/P	
1.5.1	Telephones, letters, e-mails and the Internet are freely available to service users, without censorship.	H1: A/F	Service users order and pay for their own access to these amenities, and none of these are limited, monitored or censored by the staff.

		H2: A/P	Telephones, letters, e-mails and the internet are freely available to service users, without censorship. Service users order and pay for their own access to these amenities. However, some service users complain that due to the walls being very thin they cannot have phone conversations at night time, and the privacy is also questionable due to this.
1.5.2	Service users' privacy in communications is respected.	H1: A/P	For those, who have to share their bedrooms-studio flats, their privacy becomes invaded, especially, if they receive a call at night.
		H2: A/P	For those, who have to share their bedrooms-studio flats, their privacy becomes invaded, especially, if they receive a call at night. Also the walls are thin so conversations may be overheard.
1.5.3	Service users can communicate in the language of their choice, and the facility provides support (e.g. translators) to ensure that the service users can express their needs.	H1: A/P	During the visits to the facility, the Assessment Committee members did not meet any deaf people (or any minorities who might speak in different languages). Also the team only met people whose second language is Lithuanian but they speak it fluently enough to not really know, which language is their preferred one to use with staff. According to the staff, most of staff members at least understand, if not speak Russian, and some can also speak Polish.
		H2: A/P	Similar as above.
1.5.4	Service users can receive visitors, choose who they want to see and participate in visits at any reasonable time.	H1: A/P	There are rules in this facility around this: some service users reported that they are only allowed to have family members as visitors but not their friends, others complained that their visitors are never allowed to stay overnight; visitors are expected to leave the building by 23:00 in the evening at the latest.
		H2: A/F	Visiting possibilities are very flexible in this facility. Visitors are allowed to stay overnight, come and go any time of the day, as long as they do sign in and out, especially for the first few visits.
1.5.5	Service users can move freely around the facility.	H1: A/F	
		H2: A/F	

<b>1.6</b>	<b>The facility provides a welcoming, comfortable, stimulating environment conducive to active participation and interaction.</b>	H1: A/I	
		H2: A/I	
<b>1.6.1</b>	There are ample furnishings, and they are comfortable and in good condition.	H1: A/P	One service users reported that he had had his desk broken for a while and the wall in the shower shattered for two months.
		H2: A/F	
<b>1.6.2</b>	The layout of the facility is conducive to interaction between and among service users, staff and visitors.	H1: A/I	A contrast could be felt between the coldness and inanimateness of the shared spaces and coziness of the private space in the staff room. The facility itself looks a lot like a hospital or possibly like a hostel, without any spaces for leisure or to spend time together, apart from one small 'leisure room'. The bedrooms themselves are quite small and service users reported that they are not allowed to hang any decorations or personal pictures on the walls.
		H2: A/I	The facility itself looks a lot like a hospital, or possibly like a hostel. There is a day centre in the same building, which provides space for interaction between and among service users, staff and visitors. There is not much of a conducive layout in the facility for this though, apart from its access to the day centre part of the building and one 'leisure room' downstairs in the basement area. This 'leisure room' is completely inaccessible for persons, who may have mobility problems though.
<b>1.6.3</b>	The necessary resources, including equipment, are provided by the facility to ensure that service users have opportunities to interact and participate in leisure activities.	H1: A/I	Achieved minimally. The information for service users about any potential ways to interact and participate in leisure activities is very poor. Only a info-leaflet about an upcoming concert was hung on the information board but no other more comprehensive information about the public library, free public events, etc.
		H2: A/I	Similar as above.
<b>1.6.4</b>	Rooms within the facility are specifically designated as leisure areas for service users.	H1: A/I	There is only one shared space in the facility called a 'leisure room' and few service users reported that they ever use it. This room is quite separate from the

			living rooms, and it is not very cozy. The 'leisure room' has not very much to offer – a small library, a TV set, and board games. No other options, for example, few music instruments, etc.
		H2: A/P	There is a shared 'leisure room' with sports/ training equipment, a pool table and table tennis available for service users, however, it is located in the basement of the building, which is extremely damp and mouldy, and also it is completely inaccessible for people who have mobility problems.
<b>1.7</b>	<b>Service users can enjoy fulfilling social and personal lives and remain engaged in community life and activities.</b>	H1: A/I	
		H2: A/P	
<b>1.7.1</b>	Service users can interact with other service users, including members of the opposite sex.	H1: A/F	
		H2: A/F	
<b>1.7.2</b>	Personal requests, such as to attend weddings or funerals, are facilitated by staff.	H1: A/F	
		H2: A/F	
<b>1.7.3</b>	A range of regularly scheduled, organized activities are offered in both the facility and the community that are relevant and age-appropriate.	H1: A/I	There are no <i>regularly</i> scheduled organized activities neither in the facility nor in the community. Some service users mentioned having had such activities organized from time to time in the past, however, not for a while ore recently.
		H2: A/I	Such activities do happen but not <i>regularly</i> . Some sort of activities are organized from time to time but only a part of the service users participate in them, and their appeal to service users in general could be questioned. Some of the service users, however, were very satisfied with regular activities organised in the day centre next door, and claimed them to be very useful, as well as directed towards helping them to develop skills and become more independent.



1.7.4	Staff provide information to service users about activities in the community and facilitate their access to those activities.	H1: A/I	All service users reported that there is a notice board on which staff sometimes put up some information about events in the community. At the time of the visits there was only one notice about an upcoming concert on the notice board.
		H2: A/P	Service users reported that there is a notice board, where staff put up some information. Staff do facilitate access to events in the community, if such a support is required by individual service users.
1.7.5	Staff facilitate service users' access to entertainment outside of the facility, and entertainment from the community is brought into the facility.	H1: A/I	Refer to comments above.
		H2: A/I	Refer to comments above.
2.	<b>The right to enjoyment of the highest attainable standard of physical and mental health (Article 25 of the CRPD)</b>	H1: A/P	
		H2: A/F	
2.1	<b>Facilities are available to everyone who requires treatment and support.</b>	H1: A/P	
		H2: A/F	
2.1.1	No person is <b>denied access</b> to facilities or treatment on the basis of economic factors or of his or her race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, disability, birth, age or other status.	H1: A/P	Service users have indeed been denied access to medical facilities and treatment on a basis of their disability (i.e. intellectual disability); however, not by the staff or the facility, where they live, but <b>in the community</b> , as follows: psychologists consultations were denied at the Mental Health Centre, surgery was denied at a hospital, gynaecologist's consultation was denied at a family clinic, problematic communication has been had with emergency services, such as ambulance, and they were also denied support at their psychiatrist's, when feeling suicidal. The facility's staff on their part did support service users as a result of these discriminatory practices as much as they could, and fought for them to get the medical treatment that they needed.
		H2: A/F	

2.1.2	Everyone who requests mental health treatment receives care in this facility or is referred to another facility where care can be provided.	H1: A/F	Service users are always referred to appropriate medical facilities in the community by staff, and supported to access those, if such a support is needed.
		H2: A/F	During active communication observed between the staff and service users, it appears that the staff's understanding of what mental health is must be adding to the treatment that follows the need for it by service users. Staff's attitudes towards mental health and wellbeing are somewhat outdated and based on the bio-medical approach. If a mental health crisis happens in the facility, the ambulance is called and service users are admitted to the psychiatric hospital.
2.1.3	No service user is admitted, treated or kept in the facility on the basis of his or her race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, disability, birth, age or other status.	H1: A/F	Indeed no service users are admitted or kept in the facility on this basis. However, the Assessment Committee had no opportunity to actually meet different service users of another race, colour, religion, political or other opinion, indigenous or other status. Nor blind people with intellectual disabilities or mental health problems, or deaf people. In general, the facility provides quite limited and not very varied services. It means that it is likely to not be so flexible and staff are likely to lack competences to support service users described in this criterion.
		H2: A/F	Similar as above.
2.2	<b>The facility has skilled staff and provides good-quality mental health services.</b>	H1: A/I	
		H2: A/P	
2.2.1	The facility has staff with sufficiently diverse skills to provide counselling, psychosocial rehabilitation, information, education and support to service users and their families, friends or carers, in order to promote independent living and inclusion in the community.	H1: A/I	The only staff in the facility are social workers, who act more as case managers, and the social work assistants, who have been reported to lack qualifications, and basic skills and knowledge for working with persons, who have intellectual and/or psychosocial disabilities in general. Same is applicable for the duty guards. Some efforts have been shown by staff though, as they had attended a three day training course provided by the NGO Mental Health Perspectives last year about the basics of human rights, person-centred approach, working in the community and supporting service users to live more independently. Also there is inclusion of children of service users into mainstream education services, and facilitation of

			employment for service users. Staff do indeed promote a certain level of inclusion in the community; however, not independent living in its broader global sense.
		H2: A/I	The staff do not appear to actively promote recovery or independent living in its broader global sense. Community inclusion is encouraged somewhat.
<b>2.2.2</b>	Staff are knowledgeable about the availability and role of community services and resources to promote independent living and inclusion in the community.	H1: A/I	Most of the social workers, social work assistants and duty guards attended a three-day training on this topic in 2016 provided by NGO Mental Health Perspectives. However, no real proactive implementation of this by staff has been reported by the service users.
		H2: A/I	Some service users are indeed encouraged to access some community-based services, however, they have reported that staff tend to tell them that it is best for them to stay living in the facility, rather than to search for other more independent options in the community.
<b>2.2.3</b>	Service users can consult with a psychiatrist or other specialized mental health staff when they wish to do so.	H1: A/I	Staff always support service users to approach the psychiatrist in the community Mental Health Centre, however, discriminatory practices have been reported towards the persons, who have intellectual disabilities in accessing the psychiatric care and services.
		H2: A/F	
<b>2.2.4</b>	Staff in the facility are trained and licensed to prescribe and review psychotropic medication.	H1: N/A	All medication is prescribed and reviewed in community medical facilities.
		H2: N/A	Same as above.
<b>2.2.5</b>	Staff are given training and written information on the rights of persons with mental disabilities and are familiar with international human rights standards, including the CRPD.	H1: A/I	Most of the social workers, social work assistants and duty guards attended a three-day training on this topic in 2016 provided by NGO Mental Health Perspectives. However, no real proactive implementation of this by staff has been reported by the service users.
		H2: N/I	Staff do not have any comprehensive knowledge about human rights in mental

			health, nor the UN CRPD.
2.2.6	Service users are informed of and have access to mechanisms for expressing their opinions on service provision and improvement.	H1: A/I	Both service users and staff have reported that service users do complain a lot: they do so either by directly approaching the Municipality, or they might go to the staff and/or management of the facility first. However, there are also service users who do not complain because they do not want to do so directly to the staff, being afraid of the potential negative repercussions later on.
		H2: A/I	Service users as well as staff reported that they tend to solve all the problems and complaints inside of the facility, i.e. service users complain to staff or management, and then problems get solved internally only.
2.3	<b>Treatment, psychosocial rehabilitation and links to support networks and other services are elements of a service user-driven recovery plan and contribute to a service user's ability to live independently in the community.</b>	H1: N/I	
		H2: N/I	
2.3.1	Each service user has a comprehensive, individualized recovery plan that includes his or her social, medical, employment and education goals and objectives for recovery.	H1: N/I	Service users have ‘individual plans’ and some service users have ‘person-centred plans’; however, none of the staff nor service users reported to know of what a ‘recovery plan’ means or what it might look like.
		H2: N/I	Service users have standardized individual plans, which are completed by social workers, but none of the interviewed service users were able to say what exactly is in their plan or where it is being kept. In general the staff and service users did not express that the aim of the facility is to promote recovery. Service users expressed that they are recovered and cannot live completely independently because of their social-financial situation, others (staff included) demonstrated the complete disbelief in recovery as it is understood in modern human rights terms and human rights based approach.
2.3.2	Recovery plans are driven by the service user, reflect	H1: N/I	See comments in Section 2.3.1.

	his or her choices and preferences for care, are put into effect and are reviewed and updated regularly by the service user and a staff member.	H2: N/I	See comments in Section 2.3.1.
2.3.3	As part of their recovery plans, service users are encouraged to develop advance directives which specify the treatment and recovery options they wish to have as well as those that they don't, to be used if they are unable to communicate their choices at some point in the future.	H1: N/I	See comments in Section 2.3.1. Service users are usually not aware at all of the alternatives to the treatment they are receiving. It does not seem to be discussed between them and the staff. Additionally, some staff when asked questions about 'advance directives' replied that they do indeed have those and encourage service users to have them, but then when questioned in more depth, it became apparent that they were completely unaware of what exactly the 'advance directive' was, and thus, their original answer to the question was incorrect and frankly false.
		H2: N/I	See comments in Section 2.3.1. None of interviewees mentioned ever having considered this.
2.3.4	Each service user has access to psychosocial programmes for fulfilling the social roles of his or her choice by developing the skills necessary for employment, education or other areas. Skill development is tailored to the person's recovery preferences and may include enhancement of life and self-care skills.	H1: A/I	Service users reported to have been discouraged from finding and keeping jobs. Service users are not at all encouraged to seek higher education. The only alternative they are sometimes informed of is the one of vocational training centre in Trakai town around 20 km away. Some service users felt discouraged to make any related life changes or developments and even pressured to always live 'under supervision' or simply lacked the needed support in finding employment. Any focused skill development is not observed, nor any sporadic help in some difficult situations, e.g. drop out of the school. Self-care skills and cooking skills are somewhat promoted and developed with staff's support.
		H2: A/I	Similar to the above.
2.3.5	Service users are encouraged to establish a social support network and/or maintain contact with members of their network to facilitate independent living in the community. The facility provides assistance in connecting service users with family and friends, in line with their wishes.	H1: A/I	The facility staff do provide some assistance in connecting service users with family and friends, in line with their wishes. However, there is no evidence of doing this to actually facilitate independent living in the community. There is no evidence of supporting service users' networks, and some service users claim that they cannot even imagine the staff ever asking them about their family, significant ones or friends. There appears to be very little support in strengthening liaisons

			with family members or significant others. Some service users felt that staff members are discouraging their ties to some family members or friends, and some reported that they are not allowed to have their friends visiting them in the facility only family members.
		H2: N/I	None of the service users mentioned anything of this kind.
<b>2.3.6</b>	Facilities link service users with the general health care system, other levels of mental health services, such as secondary care, and services in the community such as grants, housing, employment agencies, day-care centres and assisted residential care.	H1: A/P	Staff do encourage seeking medical help and sometimes accompany people to access medical services in the community, but there is a lack of connections with social and educational services. Staff does help service users to register in order to be placed in the queue for 'social housing' provided by the government. It is however common practice that people remain in the queue for over 10 – 15 years or more, before they are allocated a 'social flat'.
		H2: A/I	Some of the service users mentioned active part that staff takes in helping them connect to various services. No proactive support from staff to register in order to be placed in the queue for 'social housing' provided by the government was reported.
<b>2.4</b>	<b>Psychotropic medication is available, affordable and used appropriately.</b>	H1: A/P	
		H2: A/P	
<b>2.4.1</b>	The appropriate psychotropic medication (specified in the national essential medicines list) is available at the facility or can be prescribed.	H1: A/P	All medications are locked in the staff room; each service user is allocated a medication box in this room, with his/her name written on it. In case a service user needs any medication, including painkillers, they need to ask staff to let them into the staff room in order to get it. During the night all staff are out of the facility, except for the duty guard. It is not clear how accessible the medication is at night-time.
		H2: A/F	Psychotropic medication is prescribed by a psychiatrist in the community. Staff plays a role in controlling and managing some of the service users medication, e.g. reminding them to take their medicine on time. There is a nurse employed by the day centre attached to this facility, who is responsible for dispensing some service

			users medication. Service users who have their medicine at the possession of the staff and not in their bedrooms, are encouraged to be more independent since they go to the staff themselves at the time they need to take medicine without additional reminders (at least most of the time), and medication is not brought up to their bedrooms – they have to be proactive and remember too go to the nurse/ staff themselves.
2.4.2	A constant supply of essential psychotropic medication is available, in sufficient quantities to meet the needs of service users.	H1: A/F	Those who need medication get it from the community doctors, who also regularly review the prescribed medication.
		H2: A/F	Those who need medication get it from the community doctors, who also regularly review the prescribed medication.
2.4.3	Medication type and dosage are always appropriate for the clinical diagnoses of service users and are reviewed regularly.	H1: A/F	Those who need medication get it from the community doctors, who also regularly review the prescribed medication.
		H2: A/F	Those who need medication get it from the community doctors, who also regularly review the prescribed medication.
2.4.4	Service users are informed about the purpose of the medications being offered and any potential side effects.	H1: A/I	Service users have reported that they are often given the medication leaflet to read but not much more than that. Some service users reported not have even been given the leaflet and also having no idea of the side effects of the drugs they are using.
		H2: N/I	Interviewed service users could not say what medication they take, or if they did know the name of the medication, they did not know what it was for, and definitely were not aware of any potential side effects. One interviewee has claimed she neither knows what her illness is, nor what the effects of her medication are, so it was clearly not explained to her in a way she could understand it.
2.4.5	Service users are informed about treatment options that are possible alternatives to or could complement medication, such as psychotherapy.	H1: A/I	Some service users reported to have been informed of this; however, hardly anyone may afford private psychotherapy, and free psychologists' consultations at the local community Mental Health Centre were reported to have been denied to

			persons with intellectual disabilities.
		H2: N/I	The staff seem to understand the alternative treatment very narrowly and put the most emphasis on the importance of medication. At least two of the interviewed service users said that the alternatives of their treatment had never been discussed with them, neither by the facility staff nor by the psychiatrists in the community.
<b>2.5</b>	<b>Adequate services are available for general and reproductive health.</b>	H1: A/P	
		H2: A/I	
<b>2.5.1</b>	Service users are offered physical health examinations and/or screening for particular illnesses on entry to the facility and regularly thereafter.	H1: A/F	Some service users have reported not having been screened on entry and later on whereas other reported being screened.
		H2: A/I	Service users have their health monitored by the community health services, it was difficult to ascertain how much input or oversight of this the facility has.
<b>2.5.2</b>	Treatment for general health problems, including vaccinations, is available to service users at the facility or by referral.	H1: A/F	Service users are informed of such treatments as vaccinations, however, most of them cannot afford it due to the insufficient income. Nevertheless, those who do get such treatment, get it in the community health centres.
		H2: A/F	Same as above.
<b>2.5.3</b>	When surgical or medical procedures are needed that cannot be provided at the facility, there are referral mechanisms to ensure that the service users receive these health services in a timely manner.	H1: A/F	See comments in Section 2.1.1. Nevertheless, service users reported that they are all referred to the facilities, whenever that is needed in a timely manner.
		H2: A/F	
<b>2.5.4</b>	Regular health education and promotion are conducted at the facility.	H1: A/I	Some related activities were reported but not as ones conducted on a regular basis. Also the related activities were only reported to covered very few of the relevant topics.



		H2: A/I	Lectures were reported to be held irregularly with low attendance from the service users. There is a weekly cooking class held at the day centre attached to the facility, during which healthy nutrition is promoted regularly.
2.5.5	Service users are informed of and advised about reproductive health and family planning matters.	H1: A/I	Some service users live in the facility with their children and all service users are often advised about the means of contraception.
		H2: N/I	At least most of not all service users have never had any conversations with staff about reproductive health and it seemed as if it was a taboo in the facility.
2.5.6	General and reproductive health services are provided to service users with free and informed consent.	H1: A/P	See comments in Section 2.1.1.
		H2: A/F	
3.	<b>The right to exercise legal capacity and the right to personal liberty and security of person (Articles 12 and 14 of the CRPD)</b>	H1: A/P	
		H2: A/P	
3.1	<b>Service users' preferences regarding the place and form of treatment are always a priority.</b>	H1: A/I	
		H2: A/I	
3.1.1	Service users' preferences are the priority in all decisions on where they will access services.	H1: A/P	Most of the service users are registered at the same treatment location in the community. Although some also did report that they were offered to choose which clinic they would like to be treated at following them moving in to the facility.
		H2: A/P	Service users' preferences are kept in mind but the staff and service users have limited expectations on how individualised the life in the facility can be in practice.
3.1.2	All efforts are made to facilitate discharge so that service users can live in their communities.	H1: A/I	Most of the service users have been registered and are in the queue for a 'social flat' in the community; however, this procedure always takes many years, sometimes even decades, before anyone actually gets the flat and may finally move. Otherwise, it was not reported to be an active facilitation, rather an ad-hoc

			work, and service users moving out of their own accord, e.g. moving in with their partners, who rent flats in the community, etc. Some service users felt the staff have not any interest in them moving-out of the facility. Some others are not only not encouraged to move out but rather encouraged to imagine and plan how they could remain living in the facility forever, and staff do not seem to see an issue with that.
		H2: N/I	Some service users did not express a wish to move out and are happy with their life in a facility. Some service users reported that living in this facility is like living within a community, when people live alone in the room they are happy to find friends when they open their bedroom's door. Some service users have been in a queue for social housing but in Vilnius it takes many years, up to 20, to eventually get one. In terms of staff, there was no evidence found that they consider it a part of their job to encourage service users to move out to live more independently in the community. They called the facility 'a community' and 'one big family'.
<b>3.1.3</b>	Service users' preferences are the priority for all decisions on their treatment and recovery plans.	H1: A/I	Some service users do not feel like they have a voice, rather they feel they have to fit within the system's rules that usually are not flexible enough to meet their wishes. It is difficult to assess this one, since there were major differences between the positive picture which was reported by the staff and a more negative one reported by the service users.
		H2: A/I	Again, it was difficult to assess this one, since there were major differences between the positive picture which was reported by the staff and a more negative one reported by the service users. Although in this facility service users were in general a lot more positive about their image of the staff than in H1.
<b>3.2</b>	<b>Procedures and safeguards are in place to prevent detention and treatment without free and informed consent.</b>	H1: A/I	
		H2: A/I	
<b>3.2.1</b>	Admission and treatment are based on the free and	H1: N/I	It has been reported to be a standard procedure, when service users are sent to live

	informed consent of service users.		in the facility and do not really have much say or choice in the matter. This is also due to the lack of alternative options and of required support in the community. Some service users were sent to live in the facility as the only choice offered or the second one being way poorer. Others living in the facility do not feel like they would be able to move out and live elsewhere due to low income (which staff do not really encourage to raise by seeking higher education or better paid jobs) so they feel stuck in the facility rather than being able to choose where to live.
		H2: N/I	Similar as above.
3.2.2	Staff respect the advance directives of service users when providing treatment.	H1: N/I	Even though the advance directives are now in Lithuanian legislation, as of 2016, this is not used in the facility. Additionally, some staff when asked questions about ‘advance directives’ replied that they do indeed have those and encourage service users to have them, but then when questioned in more depth, it became apparent that they were completely unaware of what exactly the ‘advance directive’ was, and thus, their original answer to the question was incorrect and frankly false.
		H2: N/I	Even though the advance directives are now in Lithuanian legislation, as of 2016, this is not used in the facility. Staff were in no way familiar with the term/potential practice.
3.2.3	Service users have the right to refuse treatment.	H1: A/I	Some service users have not heard of this right at all, some think (it was not confirmed whether it is the staff view) they would be asked to move out if they refused treatment. However, in terms of medication it was reported that they may refuse to take it and staff do not force it.
		H2: A/I	In cases when staff evaluate the behaviour of service user as inadequate they will be called an ambulance and taken to a psychiatric hospital. If they refuse, they are likely to be hospitalized involuntarily. However, in terms of medication it was reported that they may refuse to take it and staff do not force it.
3.2.4	Any case of treatment or detention in a facility without	H1: N/I	

	free and informed consent is documented and reported rapidly to a legal authority.	H2: N/I	
3.2.5	People being treated or detained by a facility without their informed consent are informed about procedures for appealing their treatment or detention.	H1: N/I	
		H2: N/I	
3.2.6	Facilities support people being treated or detained without their informed consent in accessing appeals procedures and legal representation.	H1: N/I	
		H2: N/I	
3.3	<b>Service users can exercise their legal capacity and are given the support they may require to exercise their legal capacity.</b>	H1: A/P	
		H2: A/I	
3.3.1	At all times, staff interact with service users in a respectful way, recognizing their capacity to understand information and make decisions and choices.	H1: A/P	Some paternalistic attitudes and a lack of respect for service users has been observed during visits, especially from the social work assistants and duty guards' side. Antagonism between service users and staff is also visible. According to service users the staff do not always communicate with them professionally and in a respectful manner as equal with equal.
		H2: A/P	Staff do not always recognize service users' capacity to understand information. In such cases they fail to provide information in such a way that it could be understood. Staff were observed to treat mental health problems and diagnoses as a very negative thing that may happen to people, and saw it as a 'life sentence'.
3.3.2	Clear, comprehensive information about the rights of service users is provided in both written and verbal form.	H1: N/I	
		H2: N/I	
3.3.3	Clear, comprehensive information about assessment, diagnosis, treatment and recovery options is given to service users in a form that they understand and which	H1: N/I	
		H2: N/I	

	allows them to make free and informed decisions.		
3.3.4	Service users can nominate and consult with a support person or network of people of their own free choice in making decisions about admission, treatment and personal, legal, financial or other affairs, and the people selected will be recognized by the staff.	H1: A/I	Service users have a nominated social worker.
		H2: A/I	Service users have a nominated social worker.
3.3.5	Staff respect the authority of a nominated support person or network of people to communicate the decisions of the service user being supported.	H1: A/I	Service users have a nominated social worker.
		H2: A/I	Service users have a nominated social worker.
3.3.6	Supported decision-making is the predominant model, and substitute decision-making is avoided.	H1: N/I	'Supported decision-making' as such is not initiated in the facility; however, a de-facto person-centred approach is used as the main model guiding their work by some social workers.
		H2: N/I	'Supported decision-making' as such is not initiated in the facility.
3.3.7	When a service user has no support person or network of people and wishes to appoint one, the facility will help the user to access appropriate support.	H1: N/I	No evidence of this.
		H2: N/I	No evidence of this.
3.4	<b>Service users have the right to confidentiality and access to their personal health information.</b>	H1: A/P	
		H2: A/P	
3.4.1	A personal, confidential medical file is created for each service user.	H1: A/F	
		H2: A/F	
3.4.2	Service users have access to the information contained in their medical files.	H1: A/P	The personal files are available for service users to access should they want to, however, most of the interviewed service users reported that they do not know where their files are or what information exactly they contain.

		H2: A/P	In theory they do but none of the interviewed service users actually knew where their files were kept or what was in them. Some service users did not think the files could be handed to them should they ask to review the information in the files.
3.4.3	Information about service users is kept confidential.	H1: A/F	
		H2: A/F	
3.4.4	Service users can add written information, opinions and comments to their medical files without censorship.	H1: N/I	No such practices were reported by the interviewees.
		H2: N/I	Nobody in the facility seem to consider this option.
4.	<b>Freedom from torture or cruel, inhuman, or degrading treatment or punishment and from exploitation, violence and abuse (Articles 15 and 16 of the CRPD)</b>	H1: A/P	
		H2: A/P	
4.1	<b>Service users have the right to be free from verbal, mental, physical and sexual abuse and physical and emotional neglect.</b>	H1: A/P	
		H2: A/P	
4.1.1	Staff members treat service users with humanity, dignity and respect.	H1: A/I	Some paternalistic attitudes and a lack of respect for service users has been observed during visits, especially from the social work assistants and duty guards' side.
		H2: A/P	Service users were very positive about staffs behaviour and attitude towards them. However, some paternalistic and disrespectful attitudes towards service users' mental health conditions were observed during the visits.
4.1.2	No service user is subjected to verbal, physical, sexual or mental abuse.	H1: A/I	Service users as well as staff have reported that verbal as well as physical violence is quite common amongst service users in the facility. Additionally, the area where the facility is located has been reported to be 'unsafe', and several service users have experienced physical, verbal, and even sexual exploitation and abuse in the

			area around the facility.
		H2: A/I	It was reported by some service users that incidents of verbal, emotional and physical violence do occur between service users. Also the area where the facility is located has been referred to as 'unsafe', where service users have been threatened on a number of occasions.
<b>4.1.3</b>	No service user is subjected to physical or emotional neglect.	H1: A/P	It has been reported by a few service users that some of the social workers ignore them whilst they observe the same social workers communicating in a more professional manner with other service users.
		H2: A/F	
<b>4.1.4</b>	Appropriate steps are taken to prevent all instances of abuse.	H1: A/F	In the most severe cases, (especially, fights amongst the service users), the staff call the police or ambulance and the person receives all the necessary treatment needed.
		H2: A/F	Same as above.
<b>4.1.5</b>	Staff support service users who have been subjected to abuse in accessing the support they may want.	H1: A/P	It has been reported by two service users who had been abused physically that they were neither supported nor talked to about getting the support they may want or need.
		H2: A/F	
<b>4.2</b>	<b>Alternative methods are used in place of seclusion and restraint as means of de-escalating potential crises.</b>	H1: A/P	
		H2: A/P	
<b>4.2.1</b>	Service users are not subjected to seclusion or restraint.	H1: A/F	
		H2: A/F	
<b>4.2.2</b>	Alternatives to seclusion and restraint are in place at	H1: A/I	Staff do not seem to be particularly trained in de-escalation techniques. They seem

	the facility, and staff are trained in de-escalation techniques for intervening in crises and preventing harm to service users or staff.		to know some of those from life experience and common sense but definitely not from professional specialised training.
		H2: A/I	Staff have reported that they have not been trained on this and just tend to learn it by experience.
<b>4.2.3</b>	A de-escalation assessment is conducted in consultation with the service user concerned in order to identify the triggers and factors he or she find helpful in diffusing crises and to determine the preferred methods of intervention in crises.	H1: N/I	None of the service users mentioned they have ever been even asked about their preferred methods of intervention.
		H2: N/I	
<b>4.2.4</b>	The preferred methods of intervention identified by the service user concerned are readily available in a crisis and are integrated into the user's individual recovery plan.	H1: N/I	
		H2: N/I	
<b>4.2.5</b>	Any instances of seclusion or restraint are recorded (e.g. type, duration) and reported to the head of the facility and to a relevant external body.	H1: A/F	
		H2: A/F	
<b>4.3</b>	<b>Electroconvulsive therapy, psychosurgery and other medical procedures that may have permanent or irreversible effects, whether performed at the facility or referred to another facility, must not be abused and can be administered only with the free and informed consent of the service user.</b>	H1: A/F	
		H2: A/F	
<b>4.3.1</b>	No electroconvulsive therapy is given without the free and informed consent of service users.	H1: N/A	
		H2: N/A	



4.3.2	Clear, evidence-based clinical guidelines on when and how electroconvulsive therapy can or cannot be administered are available and adhered to.	H1: N/A	
		H2: N/A	
4.3.3	Electroconvulsive therapy is never used in its unmodified form (i.e. without an anaesthetic and a muscle relaxant).	H1: N/A	
		H2: N/A	
4.3.4	No minor is given electroconvulsive therapy.	H1: N/A	
		H2: N/A	
4.3.5	Psychosurgery and other irreversible treatments are not conducted without both the service user's free and informed consent and the independent approval of a board.	H1: N/A	
		H2: N/A	
4.3.6	Abortions and sterilizations are not carried out on service users without their consent.	H1: A/F	
		H2: A/F	
4.4	<b>No service user is subjected to medical or scientific experimentation without his or her informed consent.</b>	H1: A/F	
		H2: A/F	
4.4.1	Medical or scientific experimentation is conducted only with the free and informed consent of service users.	H1: N/A	
		H2: N/A	
4.4.2	Staff do not receive any privileges, compensation or remuneration in exchange for encouraging or recruiting service users to participate in medical or scientific experimentation.	H1: N/A	
		H2: N/A	

4.4.3	Medical or scientific experimentation is not undertaken if it is potentially harmful or dangerous to the service user.	H1: N/A	
		H2: N/A	
4.4.4	Any medical or scientific experimentation is approved by an independent ethics committee.	H1: N/A	
		H2: N/A	
4.5	<b>Safeguards are in place to prevent torture or cruel, inhuman or degrading treatment and other forms of ill-treatment and abuse.</b>	H1: A/I	
		H2: A/I	
4.5.1	Service users are informed of and have access to procedures to file appeals and complaints, on a confidential basis, to an outside, independent legal body on issues related to neglect, abuse, seclusion or restraint, admission or treatment without informed consent and other relevant matters.	H1: A/F	
		H2: N/I	
4.5.2	Service users are safe from negative repercussions resulting from complaints they may file.	H1: A/P	Some service users do not feel this way even if they have not even tried to complain. They feel the staff to be prejudiced enough as they are and feel they would receive negative repercussions if they were to file a complaint.
		H2: A/F	
4.5.3	Service users have access to legal representatives and can meet with them confidentially.	H1: N/I	There were a few service users who had been in need of finding a lawyer at one time in the past, however, they said they were not informed by staff on how to access one, especially if a shortage of personal money was the case. They were not informed of organisations fighting for human rights that might be able to assist them for a lower fee or pro-bono.
		H2: N/I	
4.5.4	Service users have access to advocates to inform them	H1: N/I	

	of their rights, discuss problems and support them in exercising their human rights and filing appeals and complaints.	H2: N/I	
4.5.5	Disciplinary and/or legal action is taken against any person found to be abusing or neglecting service users.	H1: A/F	
		H2: N/I	No evidence of this.
4.5.6	The facility is monitored by an independent authority to prevent the occurrence of ill-treatment.	H1: N/I	A few of the service users have talked about some authority coming to inspect the facility and ill treatments cases, however, they did not seem to conduct any thorough interviews with service users what so ever. It was not an independent body though, as the authority in question is the Municipality, which owns and funds these services.
		H2: N/I	Same as above.
5.	<b>The right to live independently and be included in the community (Article 19 of the CRPD)</b>	H1: A/I	
		H2: A/I	
5.1	<b>Service users are supported in gaining access to a place to live and have the financial resources necessary to live in the community.</b>	H1: A/I	
		H2: N/I	
5.1.1	Staff inform service users about options for housing and financial resources.	H1: A/I	As described in the comments in Section 3.1.2., the only option explored and pro-actively addressed by staff is registration to get in a queue for a ‘social flat’. The ‘social flat’ itself may not be the best option, however, other options of housing have not really been reported to have been explored and definitely not on a regular basis. Most of the time the active work has to first come from the service user, e.g. who expresses their wish to move out from the facility and move in with their partner in the community. The facility does not seem to be understood or treated by staff as an interim service between the service users leaving a long-term social care or psychiatric institution and starting to live more independently in the community. In terms of financial resources, staff do inform service users of

			options and support them to access those.
		H2: A/I	Staff do help and inform service users about options for financial resources. However, housing options are explored very minimally. It must be noted that realistically there are extremely limited options for housing for service users of both these facilities in the context of the current social care and mental health care systems. I.e. there is extremely limited support that people could get if living in a flat in the community.
5.1.2	Staff support service users in accessing and maintaining safe, affordable, decent housing.	H1: A/I	See comments in Section 3.1.2. and 5.1.1.
		H2: A/I	See comments in Section 3.1.2. and 5.1.1. The main problem is that what staff can do is also limited by the systemic issues and challenges, and the lack of effective and accessible community-based services in the country.
5.1.3	Staff support service users in accessing the financial resources necessary to live in the community.	H1: A/I	Staff do support service users to access their benefits and some service users have been supported to look for a job. However, these efforts were reported to be quite sporadic and not so pro-active on the staff's side. Also staff help service users to manage their budget and finances; staff help them with shopping and avoiding or repaying debt.
		H2: A/I	Staff have been report to have helped some of the service users to find a job. Also staff help to manage the service users' finances, help them with shopping and avoiding or repaying debt.
5.2	<b>Service users can access education and employment opportunities.</b>	H1: A/I	
		H2: A/I	
5.2.1	Staff give service users information about education and employment opportunities in the community.	H1: A/I	Staff appear to be favouring some specialised education facilities, and very little mainstream education if any is offered to the service users. This again is a systemic problem in the country.
		H2: A/I	Staff do advice people about this, however, it is mostly on demand and not in a

			pro-active way.
5.2.2	Staff support service users in accessing education opportunities, including primary, secondary and post-secondary education.	H1: A/I	Most of the staff only support service users to access segregated and specialised vocational training centres. Again, such a support is often provided on demand and not in a pro-active way.
		H2: A/I	Similar as above.
5.2.3	Staff support service users in career development and in accessing paid employment opportunities.	H1: A/I	Some support is provided in this area. However, some of the staff have been reported to have been discouraging and even making fun of service users trying to access paid employment opportunities.
		H2: A/I	Some support is provided but it is mostly down to the pro-activity of the service users themselves.
5.3	<b>The right of service users to participate in political and public life and to exercise freedom of association is supported.</b>	H1: A/I	
		H2: A/P	
5.3.1	Staff give service users the information necessary for them to participate fully in political and public life and to enjoy the benefits of freedom of association.	H1: A/I	Some informational leaflets have been reported to have been shared with service users by staff. These are hardly ever produced in an <i>Easy-to-Read</i> format.
		H2: A/I	Some information gets disseminated and sometimes some discussions take place amongst service users.
5.3.2	Staff support service users in exercising their right to vote.	H1: A/P	Service users are given their passports (that are normally kept in safe in the staff room) and voting cards by staff, and then they all together go to vote in the community voting stations. It was reported that not all of the service users actually require such an assistance, nevertheless, everyone is organized together to go voting as a group, rather than completely independently.
		H2: A/F	
5.3.3	Staff support service users in joining and participating	H1: N/I	

	in the activities of political, religious, social, disability and mental disability organizations and other groups.	H2: N/I	
5.4	<b>Service users are supported in taking part in social, cultural, religious and leisure activities.</b>	H1: A/I	
		H2: A/P	
5.4.1	Staff give service users information on the social, cultural, religious and leisure activity options available.	H1: A/I	See comments in Section 1.7.4.
		H2: A/P	See comments in Section 1.7.4. Some service users do feel they have an active social life in the facility (especially with it being in the same building as a day centre) and staff organising group outings to events in the community.
5.4.2	Staff support service users in participating in the social and leisure activities of their choice.	H1: A/P	Some of the staff do support some of the service users to go out to some social and leisure activities. Sometimes as a group activity though, rather than an individual one-to-one support.
		H2: A/F	When such a support is needed, staff do provide it.
5.4.3	Staff support service users in participating in the cultural and religious activities of their choice.	H1: A/F	
		H2: A/F	

## **Discussion**

### ***The Right to an Adequate Standard of Living (Article 28 of the UN CRPD)***

#### **Good Practice Examples**

Although the buildings of both facilities are over 30 years old, they were renovated before the opening of the independent living services in 2013. Resources from Structural funds, Municipal and State budget were invested in order to improve the physical state of the buildings, and to create the very first community-based services of this type, which people with disabilities could call their home.

The standard of living inside of both facilities is relatively high, if compared with the large residential social care institutions in the country: there is a total of 26 service users currently living in Home 1, and 27 in Home 2; service users have single, double or triple bedrooms-studio flats with a personal kitchen and *en-suite* bathroom in each apartment. Couples are supported to move in together, if they express such a wish. Also parents are allowed to live with their underage children, even if the child does not have a disability, only the mother or father. Service users' privacy is respected, they have personal keys for their bedrooms-studio flats, and staff must knock and wait for a permission to enter from the service user every time. Service users' right to refuse to let staff in, should they wish to do so, is respected.

#### **Challenges**

The very first thing that may be observed when approaching the facilities is that they are on the same road, opposite each other, and only a few hundred meters apart. Another important factor, which sparked a discussion amongst the Assessment Committee's members is the area of the city, where the facilities are located, itself. It may be described by some as a location on the outskirts of the city, although still connected with scarce options for public transport; and in terms of travel time it is in fact not too far from the city centre. In order to avoid potentially stigmatizing the area itself, the Assessment Committee decided to only focus on the fact that a lot of different types of social care and psychiatric care facilities for various different groups of vulnerable and marginalised people, including one of the largest psychiatric hospitals in the country, are currently concentrated in this area. This in its turn suggests a form of segregation from mainstream society and from the general community of the capital city. Such services provided in segregation pose a higher risk of human rights violations (UN Economic and Social Council, 2005). Also this system of services for vulnerable people being all concentrated in this one specific area is an example of the segregation and centralization of mental health services around psychiatric hospitals and other related institutions, which continues to pose a challenge in a lot of important human rights related respects (UN High Commissioner for Human Rights, 2017).

Moreover, one of the main challenges identified by the Assessment Committee with regards to the service users' right to an adequate standard of living was the fact that even though a lot

of investment has gone into the improvement of the physical state of the facilities, very little has so far been invested into the training and raising the qualifications of the staff. This is a systemic issue, as well as that of each one of the facilities itself and its management. Home 1 in this sense have reported to have had slightly more attempts at training their staff, as compared to the Home 2. However, in general, employees of both services would benefit from more advanced theoretical, ideological and practical training. This is especially relevant when talking about their lack of knowledge and understanding of human rights of service users, and matters related to the UN CRPD, recovery theory, supported decision making, person-centred approach and (bio-psycho)social model.

The comprehensive view and human rights based approach to services' delivery was identified to be lacking amongst the interviewed staff and in the general atmosphere in both facilities. Relating both to the individuals' rights envisaged in Article 28 and Article 19 of the UN CRPD, in order to ensure an adequate standard of living, housing and comprehensive social protection policies are vital. This includes receiving needed *assistance* for housing, family, inclusion in the open labour market, with all reasonable accommodations ensured in the workplace, elimination of poverty, malnutrition and also of social exclusion, all of which play an important role and have a positive impact on every person's mental health and general well-being (UN High Commissioner for Human Rights, 2017). Even though in Home 2 the general atmosphere was observed to be a lot more relaxed and less regimented than in Home 1, nevertheless, the pro-activeness of staff to provide the above described type of comprehensive assistance was missing in both facilities. Staff's efforts to provide any related support in some cases was also observed to be mostly coming from their own choices, rather than from the pro-actively obtained needs and wants of the service users, especially so in Home 1. This in its turn was observed to create a potentially false idea amongst the staff that service users are not interested in what there is on offer, which gradually seems to have made staff less likely to come up with new ideas or suggestions for action or activities at all.

### ***The Right to Enjoyment of the Highest Attainable Standard of Physical and Mental Health (Article 25 of the UN CRPD)***

#### **Good Practice Examples**

In both facilities staff support service users to access health care facilities in the community. Especially in Home 1 both staff and services reported that extended efforts had been made by the facility's employees to provide this type of support. Due to the fact that service users have intellectual disabilities as well as mental health problems in Home 1, they reported to have experienced on a number of occasions disability based discrimination in medical facilities in the community. For example, a staff member reported that service users were "on several occasions denied psychological treatment and support at the local Mental Health Centre; this had been reasoned by the medical facility's staff as not having been '*purposeful*', since service users have intellectual disabilities and 'do not understand anything: the psychologist support is effective when provided to *healthy* people, not those who will not understand anything and there will be no result achieved'". This and similar situations were repeated by



several staff during the interviews at Home 1. In such cases, when they were denied treatment, such as surgeries, gynaecologist's consultations, and support when feeling suicidal, the facility's staff were very pro-active and mediated between service users and medical staff in the community. They managed each case individually and ensured that service users' right to health would be respected, and that the needed treatment would be provided. It is true that across the world individuals, who have mental health problems, experience disproportionately higher rates of poor physical health and such health conditions are often left unattended (WHO, 2013); hence, by their actions the facility's staff very positively contributed to making medical services in the community generally more accessible for people, who have disabilities and mental health problems.

## Challenges

It is apparent from observations, documents review and interviews conducted with both service users and staff that matters related to physical health and service users' right to the highest attainable standard of specifically *physical health* is mostly ensured in both facilities more than that of *mental health*. Staff truly fight for service users' access to adequate health care services in the community. However, at the same time staff in both facilities reported that they have not had training on mental health crisis management, anger management or any other similar interventions, nor on prevention techniques. In cases of mental health crisis, the main measure used by staff in both facilities is calling an ambulance and taking service users to psychiatric hospitals for treatment. It is a fact that the predominant model and methods of treatment are based on the bio-medical model in such hospitals in Lithuania. This situation indicates facilities staff's approach, which is based more on the bio-medical paradigm and not on human rights based approach. It is possible that this is due to physical health as such being easier to emphasize with for the staff than mental health, and also it being easier to measure and monitor.

Additionally, the challenge identified in the section above related to the lack of training for staff may be at fault too, as illustrated by the attitude towards mental health in general expressed by one of the staff members in the following way: "*...mental illness is such a thing that once you get it – that is it, there is no way to get better. Even with depression, you may try to cure it but eventually it will display itself in a form of either one's mood or behaviour... our service users have been deemed to have a disability by the respective authorities for a reason... sometimes the emotional state of persons gets better... though the illness remains*".

The prevalence of mental health conditions continues to grow across the world with significant impact on health and social, economic and human rights consequences (WHO, 2017). It is a common health condition that has a potential to affect any person at any given time; nevertheless recovery is possible and even common (Boevink, 2017). Hence, staff who work in facilities that provide support to individuals, who have mental health problems or psychosocial disabilities, are ought to be sensitive, aware and skilled enough to emphasize with what mental health and well-being is, through a more of a recovery based approach, in order to provide such services in a more effective way. It is important to note that mental

health is not merely a health issue, and there is a range of factors that affect mental health and contribute to recovery. Moreover, mental health is often linked to poverty and the economic hardship: these personal challenges often arise as a result from “the inadequate realization of economic, social and cultural rights, such as the rights to education, work, housing, food and water“ (UN Human Rights Council, 2017). The right to health is inclusive to both health care and the underlying social determinants of health, and this is where public health has a major role, through both the individual and collective dimensions (UN Human Rights Council, 2017; UN Committee on Economic, Social and Cultural Rights, 2000).

The right of everyone to health entitles individuals to a *health system* that supports the attainment of *the highest level of health* (UN High Commissioner for Human Rights, 2017). Nevertheless, another challenge identified is once again a system based one. The mere fact that people, who have intellectual disabilities, face discrimination even from medical doctors and professionals in the community, points to the fact that mental health related stigma is still a major issue in Lithuania. Across the world stigma has been reported as a significant determinant of “*quality of care and access to the full range of services required by persons with mental health conditions who also have physical complaints*“ (Lawrence and Coghlan, 2002). In the examples of such discrimination and negative attitudes towards service users described above, it is apparent that there is no difference for the community medical staff, whether people who have come to seek treatment from them are residents of the historical segregated social care institutions or they are residents of an ‘Independent Living’ facility – the judgemental and stigmatizing attitudes towards people with disabilities are the same. This is in violation of international human rights principles. As per UN CRPD, which has been ratified in Lithuania since 2010: “*the human rights-based approach to disability, in addition to other principles, requires the unconditional application of the principle of non-discrimination with regard to persons with disabilities. No additional qualifiers associated with an impairment may justify the restriction of human rights*“ (UN High Commissioner for Human Rights, 2017).

Additionally, the question of adapting and using techniques and various existing models of comprehensive human rights based interventions, examples of which may be obtained from global practices and related evidence-base, is raised. Staff in the assessed facilities lack training, knowledge and skills on how to effectively provide mental health first aid, manage mental health crisis situations or anger outbursts of service users. Instead of managing such incidents within the facility, use preventative measures or de-escalation techniques, they call an ambulance or police and rely upon these external emergency services to solve such challenges. This is not just a problem of these two facilities, it is deeply related to systemic gaps in the general provision of social care and mental health services in Lithuania, and what is expected of those by the State.

In terms of medication management, service users are mostly not allowed to keep their medications in their own bedrooms-studio flats in both facilities, and especially in Home 1. Medication is kept in staff rooms and service users have to come in to take it at certain times

every day. In this sense, the system and rules in these facilities are very much similar to those used in other larger social care and psychiatric institutions.

Some service users in Home 1 reported to have been informed of treatment options that are possible alternatives to or could complement medication, such as psychotherapy. However, hardly anyone may afford private psychotherapy, and free psychologists' consultations at the local community Mental Health Centre were reported to have been denied to persons with intellectual disabilities. In Home 2 though staff seemed to understand the alternative treatment very narrowly and put the most emphasis on the importance of medication. At least two of the interviewed service users said that the alternatives to their treatment had never been discussed with them, neither by the facility staff nor by the psychiatrists in the community. This was identified as an important issue by the Assessment Committee, since while psychotropic medications can be helpful, there are also potential side effects to them, and in many cases they could be avoided in the first place: *“Prescribing psychotropic medications, not because they are indicated and needed, but because effective psychosocial and public health interventions are not available, is incompatible with the right to health. For example, in most cases of mild and moderate depression ‘watchful waiting’, psychosocial support and psychotherapy should be the frontline treatments”* (UN Human Rights Council, 2017). Unfortunately, the State budget for covering non-medical costs is very low due to the poor provision of such required services, and social care system also does not ensure investment in (psycho)social rehabilitation and elimination of social exclusion (Petruzyte and Sumskiene, 2017).

In order to address such systemic challenges and inequities in health and related social care systems, the State could employ such frameworks as the 2030 Agenda for Sustainable Development and the Sustainable Development Goals. These provide an opportunity to improve the health and human rights of the most vulnerable groups. Additionally human rights approach and the right-to-health framework could contribute to their effective implementation and achievement for all individuals in need (UN General Assembly, 2016).

### ***The Right to Exercise Legal Capacity and the Right to Personal Liberty and the Security of the Person (Articles 12 and 14 of the UN CRPD)***

#### **Good Practice Examples**

None of the service users, who live in both facilities, have been deprived of their legal capacity.

#### **Challenges**

The reform in legal capacity related national legislation was implemented recently in the country, and the Advance Directives are now something that could be used in all services as of 2016. Advance planning refers to *“the process of making known one’s choices and preferences about future care or treatment, and ensuring that other people are aware of these choices. Advance plans are sometimes called living wills or advance directives. They apply*

*during times when people may be having important difficulties in making or communicating decisions“* (WHO QualityRights, 2017). However, at the time of the interviews none of the staff in either of the two facilities were familiar with such an option for support that they may provide to service users.

It should be noted that some staff when asked questions about ‘advance directives’ replied that they do indeed have those and encourage service users to complete them. However, when questioned in more depth, it became apparent that they were completely unaware of what exactly an ‘advance directive’ was. Thus, their original answer to the question was incorrect and frankly false. In Home 2 staff were too in no way familiar with the term or potential practice related to ‘advance directives’. Moreover, ‘supported decision-making’ as such is not at all initiated in either of the facilities; nevertheless, a de-facto person-centred approach is used as the main model guiding the work by some social workers in Home 1.

In addition to the above, discriminatory attitudes are still prevalent amongst some of the staff, who report that some service users due to their disability should be deprived of their legal capacity. This is not in line with the principles of the UN CRPD and its General Comment No. 1, which clearly states that:

*“the denial of legal capacity to persons with disabilities has, in many cases, led to their being deprived of many fundamental rights, including the right to vote, the right to marry and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty“, and so „there are no permissible circumstances under international human rights law in which a person may be deprived of the right to recognition as a person before the law, or in which this right may be limited“* (Committee on the Rights of Persons with Disabilities, 2014).

Admission to both facilities was observed not to be based on the free and informed consent of service users. In both facilities it was reported to be a standard procedure, when service users are sent to live in the facility by their social worker and do not really have much say or choice in the matter. This is also due to the systemic problems, and a lack of alternative options for required support to be provided in the community. Some service users were sent to live in the facility as the only option available and offered or the second one being way poorer, for example, a large segregated social care institution. Others living in the facility do not feel like they would be able to move out and live elsewhere due to their low personal income (which staff unfortunately do not seem to really encourage to raise, for example, by seeking higher education or better paid jobs), so they feel stuck in the facility rather than being able to choose where or with whom to live.

Some service users reported that they do not feel like they have a voice, rather they feel that they have to fit within the system’s rules, which are not flexible enough to meet their wishes. In general it was difficult for the Assessment Committee to assess whether service users’ preferences are the priority for all decisions on their treatment and recovery, since there were major differences between the positive picture which was reported by the staff and a more negative one reported by the service users. It was the case in both facilities, although in Home

2 service users were generally a lot more positive about their image of the staff than those in Home 1.

From observations it may be noted that staff in both homes do tend to interact with service users in a respectful way, recognizing their capacity to understand most of information and make decisions and choices. Nevertheless, some paternalistic attitudes and a lack of respect for service users was also observed during visits, especially from the social work assistants and duty guards' side in Home 1. Antagonism between service users and staff was also visible. According to service users, the staff do not always communicate with them professionally and in a respectful manner as an equal with an equal. In Home 2 staff did not seem to always recognize service users' capacity to understand information, however, in such cases they appeared to in fact struggle to provide the information in such a way that it could be understood by individual service users. Staff were observed to treat mental health problems and diagnoses as a very negative matter in itself in Home 2, and reported to see it as a 'life sentence'.

In terms of the personal files, those are available for service users to access in both facilities should they wish to do so. However, most of the interviewed service users reported that they do not know where their files are or what information exactly they contain. Additionally, when asked whether service users are encouraged to add to their own files or contribute to their completion in any way, staff in both facilities, but especially in Home 2, appeared perplexed and reported not to have ever considered such a practice.

Reflecting on all of the above, it should be noted that the right of every person to legal capacity should be recognised on both the legal and individual basis. All forms of substitute decision-making should be replaced by supported decision-making arrangements, which would ensure people remain at the centre of their own decisions and that every person's right to make those is respected (Angelova-Mladenova, 2017). In some cases, where the will of the individual concerned might be difficult to ascertain, such instruments as advance directives or powers of attorney could be fostered (UN High Commissioner for Human Rights, 2017). All possible and significant efforts should be made in order to determine the individual's will, choices 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”* (UN Committee on the Rights of Persons with Disabilities, 2014).

## ***Freedom from Torture or Cruel, Inhuman or Degrading Treatment or Punishment and from Exploitation, Violence and Abuse (Articles 15 and 16 of the UN CRPD)***

### **Good Practice Examples**

In the most severe cases, (especially, fights amongst the service users), the staff off both facilities call the police or ambulance and the person receives all the necessary treatment needed. Additionally, in Home 1 service users are informed of and have access to procedures to file complaints, on a confidential basis, to an outside, responsible body, i.e. the Municipality, on issues related to neglect, abuse, seclusion or restraint, admission or treatment without informed consent and other relevant matters. Service users are safe from negative repercussions resulting from complaints they may file. Service users in Home 2 also have such an option and have been informed of the possibility to file complaints, however, less instances of such complaints was reported in Home 2, when compared with Home 1.

### **Challenges**

In both facilities staff members were observed to treat service users with humanity, dignity and respect. However, some paternalistic attitudes towards service users has been noticed during visits, especially from the social work assistants and duty guards' side in Home 1. Service users were very positive about staffs behaviour and attitude towards them in Home 2; however, some paternalistic and disrespectful attitudes towards service users' mental health conditions were too observed during the visits.

Service users as well as staff in both homes reported that verbal as well as physical violence is a common occurrence amongst service users within these facilities, and especially so in the Home 1. Additionally, the area where the facilities are located has been reported to be 'unsafe', and several service users have experienced physical, verbal, and even sexual exploitation and abuse in the area around the facilities. Nevertheless, appropriate steps are taken to prevent all instances of abuse as much as possible, and in the most severe cases, the staff call the police or ambulance and the person receives all the necessary treatment.

Issues have been identified by the Assessment Committee on the systemic level, in cases where service users needed access to legal representatives, as a result of experiencing abuse or ill-treatment in the community. The free legal aid, which would be accessible for person, who have mental health problems, intellectual or psychosocial disabilities, is very limited in Lithuania. In Home 1 there were a few service users, who had been in need of finding a lawyer in the past, however, they said they were not informed by staff on how to access one, especially if a shortage of personal funds was the case. They were not informed of organisations fighting for human rights that might be able to assist them for a lower fee or pro-bono either.

Moreover, in both facilities staff are not trained on alternatives to seclusion and restraint nor on de-escalation techniques for intervening in crises and preventing harm to service users or staff. Staff reported to know of those from life experience and common sense but not from professional specialised training. A de-escalation assessment is not conducted in either of the two facilities in consultation with the service user concerned in order to identify the triggers and factors he or she may find helpful in diffusing crises and to determine the preferred methods of intervention in crises. None of the service users mentioned they have ever been even asked about their preferred methods of intervention.

It should be noted here that choosing alternative methods and eliminating practices of seclusion and restraint does not mean that efforts are not needed to support a person not to hurt themselves or others. Nevertheless, it is important to recognise the difference between protective tools and practices of restraint: “*Protective actions or devices are different from restraint in that they are acceptable to the person, are non-coercive, and are used with the informed consent of the person*“ (WHO QualityRights, 2017:2). Such alternative methods may include the following: holding a person’s hand or arm to prevent them from falling; wearing a helmet for head protection by a person who has seizures; wheelchair seatbelt worn by a person with a history of falling forward; using a leg or arm splint to maintain proper body positioning or to promote healing; casts or orthopaedic devices; use of de-escalation techniques, sensory approaches and/or comfort rooms (WHO QualityRights, 2017:2).

Finally, the facilities are not monitored by an *independent authority* to prevent the occurrence of ill-treatment. A few of the service users have talked about some authority coming to inspect Home 1 and the suspected ill-treatment cases that had allegedly occurred there; however, they did not seem to conduct any thorough interviews with service users what so ever. It was not an independent body though, as the authority in question is the Municipality, which is responsible for and provides funding to these services.

### ***The Right to Live Independently and be Included in the Community (Article 19 of the UN CRPD)***

#### **Good Practice Examples**

The recognition of the need to create new community-based more independent living-type services instead of institutional care facilities in itself is a positive occurrence in Lithuania. The commitment of the government demonstrated in a form of the Action Plan (2014-2020) for the Transition from Institutional Care to Community-Based Services for Persons with Disabilities and Children Left without Parental Care is a right step towards the implementation of country’s obligations under the UN CRPD.

In a more local context of the two assessed facilities, some modern attitudes towards mental health, human rights and person-centred approach to providing support in the community was demonstrated by Home 1 in particular. Management of this service ordered training on these and related topics from NGO Mental Health Perspectives in Vilnius for their staff in 2016.

Additionally, staff in both facilities demonstrated a positive will to support service users to live their lives as independently as possible; they provide support with day-to-day tasks and personal skills development to a certain degree. Such daily tasks as budgeting, managing the available financial resources, avoiding and repaying debt, shopping, and cooking are assisted with by the staff. Staff were reported to have helped some of the service users to find a job and/or education opportunities, be it mostly specialised vocational training options and/or education provided in segregated settings. Moreover, staff give service users the information necessary for them to participate in political and public life: some informational leaflets were reported to have been shared with service users by staff prior to national and local elections. These are hardly ever produced in an *Easy-to-Read* format though. Nevertheless, some information gets disseminated and sometimes some political discussions take place amongst service users. Staff support service users in exercising their right to vote by escorting them to the voting stations on election days. Staff also support service users in participating in the cultural and religious activities of their choice.

## Challenges

To begin with it is important to note that the only definition of community services in Lithuania is that described in the Action Plan (2014-2020) for the Transition from Institutional Care to Community-Based Services for Persons with Disabilities and Children Left without Parental Care as “*services of various types and forms, which are alternative to institutional care. These include community-based services that provide social, healthcare, education, or cultural support, which ensures that every person has an opportunity to live in the community and get all the needed specialised help and assistance that meets his or her individual needs*”. Additionally, the definition mentions the need of such services to foster independent living, social inclusion and full participation in society.

The above outlined definition is partially in line with the UN CRPD, however, development of community-based services requires both a political and social approaches: not only does it consist of creating new services in the community that are more *specialised* and provided specifically to certain groups of vulnerable people. It also involves broader policy measures that are necessary for ensuring that all existing public services, such as housing, education, transportation, health care and other services and support, are available and accessible to persons, who have disabilities, to use in mainstream settings, and live as full and equal citizens (Angelova-Mladenova, 2017). In many cases, group homes, such as the two assessed ‘Independent Living Homes’ *do not* support independent living: “*where they are provided, they must form part of a range of community-based services that offer genuine, adequately funded independent living options*“ (Angelova-Mladenova, 2017).

All of the above points to a very complex and systemic picture, without certain pillars of which no support to persons, who have mental health problems, intellectual and/or psychosocial disabilities, can be truly in line with the vision outlined in the UN CRPD. This can only be ensured, if it is rooted in the comprehensive human rights based approach, and if it fosters full choice, control, authenticity, and full inclusion of every person in society. The



plan envisaged in the Lithuanian Action Plan (2014-2020) is to start development of community-based services in the regions of the country as of 2018. However, the main gap in this particular part of the Plan is that it does not put enough emphasis on a) human rights based approach in the new models of support and specialised services that are being developed; and b) it lacks emphasis on the broader picture and policy measures that would ensure that in parallel the accessibility of existing mainstream services that are already provided in the community is increased significantly. For example, any construction and building projects should already be covered by mainstream policies, plans and programmes, which include the dimension of addressing the needs of people who have disabilities. Thus, any newly built building in general should be built so it is accessible to persons with disabilities. Additionally, any training for professionals should include mental health, disability, and most importantly – human rights related topics (Angelova-Mladenova, 2017).

When analysing the risks involved in establishing new services, such as the two assessed ‘Independent Living Homes’ a number of factors arise. Across the world deinstitutionalization is a lot of the time interpreted as merely closing-down of large long-term residential institutions. Hence, the closure of these institutions is often understood to be the factor that automatically facilitates individuals’ independent living and inclusion in the community. As a result, persons who have disabilities are moved out from institutions, with little attention being paid to the development of a comprehensive network of support services and to making the existing community services accessible, as described above. The main risk is then for the ‘group-home’ type of settings, to which individuals get moved, to become a new form of a long-term facility with very similar features of institutional culture practiced in it, be it a much smaller establishment. Such new ‘group home’ settings are *“...commonly presented as a ‘stepping stone’ to real life in the community, but remain a permanent ‘home’ for people leaving institutions. In the context of poorly developed support options, their existence encourages the ‘placement’ of disabled people and prevents real inclusion ... Many countries ‘are showing worrying trends of grouping apartments into residential compounds, comprised of dozens of units targeted exclusively at people with disabilities”* (Mulheir, 2015; Angelova-Mladenova, 2017).

The abovementioned risk points to the real potential of any newly built ‘group homes’, or such facilities as the two assessed ‘Independent Living Homes’, to become a follow-up of a prototype of an institution, be it a ‘mini’ model of it. According to global evidence-base and best practice examples, investments into such and similar specialised services should not be prioritised during deinstitutionalisation: residential services, such as these, should be one of the options, alongside other genuine independent living opportunities and accessible mainstream services in the community (European Coalition for Community Living, 2009; Angelova-Mladenova, 2017). Moreover, the element of ‘choice’ is often missed out of the equation: individuals have a right to truly *choose* where and with whom they live. Having such an autonomy promotes inclusion in the community. On the other hand *“institutionalized living arrangements, whether in large facilities or smaller group homes, amount to segregation and are inconsistent with inclusion in the community”* (UN High Commissioner for Human Rights, 2017).

The Assessment Committee, most members of which had monitored human rights conditions in large residential long-term social care institutions in the past, came to an agreement that all the risks and factors outlined above are relevant in the case of the two 'Independent Living Homes' in Vilnius. Even though it is presented as potentially being a 'stepping stone' or a 'halfway home' for some service users to eventually move out to live more independently in the community, the reality in practice is very different. Results from observations, document reviews, and interviews with both staff and service users show that there are in fact no further algorithms created nor other clear options or accessible services in the community. The systemic gaps programme such new services to become the new '*norm*', which simply replaces the old large long-term residential institutions with the new smaller ones. Moreover, these new services are only foreseen and provided to the 'most independent' service users, who have mild to moderate disabilities. The individuals with more severe conditions, according to the current deinstitutionalization plan, are going to remain living in large institutions of up to 150 – 200 residents, sometimes even more, dotted across Lithuania.

Another major systemic issue is the lack of inter-sectoral collaboration in implementation of both the deinstitutionalization in the country and the UN CRPD in general. Currently a new methodology for 'group home' and 'independent living' type of settings is being developed at the Ministry of Social Security and Labour. Its aim is to make such services a part of a 'chain', to create an algorithm, which would ensure the person's path through appropriate levels of specialised services but also, necessarily, the eventual independent living and full inclusion in society and participation in the community. This new methodology development currently does not involve a comprehensive inter-sectoral collaboration between the named ministry and the Ministry of Health, as well as Municipalities, and other key stakeholders. Additionally, here it is important to note that 'independent living' in Lithuania is often understood as a synonym to 'living alone', which is not necessarily true in cases of persons, who have various disabilities. 'Independent living' in such cases is living in the community with needed, appropriate and adequate support available and accessible to the person.

Going back to the assessment of the two particular services in Vilnius, it was apparent throughout the study that all the systemic issues described above apply in this case. For example, the only option explored and pro-actively addressed by the staff of Home 1 in order to help service users to move to a more independent living in the community, was helping them to register in order to get in a queue for a 'social flat'. It takes years and sometimes decades to eventually be appointed one of these flats in practice. A 'social flat' itself may not be the best option, however, other options of housing were not really reported to have been explored and definitely not on a regular basis. Most of the time the active work has to first come from the service user, for example, one who expresses their wish to move out from the facility and move in with their partner in the community. The facility does not seem to be understood or treated by staff as an interim service between the service users leaving a long-term social care or psychiatric institutions and starting to live more independently in the community. In terms of financial resources, staff do inform service users of options and support them to access those; however, this is not done with an intent to enable them to move

out, but rather in order to survive in general. In Home 2 housing options are also explored very minimally. The main reported problem from staff's side is the fact that there is extremely limited support available that people could get if they were living more independently, for example, in a flat in the community. Hence, they would be essentially left completely alone, without the support they need, were they to move out of the facility.

One of the main types of support still missing in the community in Lithuania is personal assistance. This type of community-based support is crucial in the case of persons, who have mental health problems, intellectual and/or psychosocial disabilities, and when ensured to be of high standard and human rights based, can be extremely effective:

*“Personal assistance is empowering, flexible and desirable for both employers and workers, when it goes well.... we need to give both disabled employers and personal assistants the skills and knowledge they need to manage these relationships effectively ...Respect difference – respect the personality and values of other people; be willing to accommodate difference, be that personality, culture or ways of practice. Tolerance may also extent to things not always being done exactly as you would do them yourself”* (Shakespeare et al., 2017).

Even in the ‘Independent Living Homes’ staff could potentially provide their support in a more person-centred way and based on the personal assistance model. It could include the recovery based approach, which would mean that persons with mental health problems and disabilities would be recognized as individuals, who can be supported to achieve their own aspirations and goals, realize their own potential and act upon it, guide their own path in life, be empowered, and focus on the strengths they possess, rather than limitations. Thus, recovery in this sense does not mean ‘being cured’ but it is rather about learning to live with your own condition and gaining new meaning and purpose in life (WHO QualityRights, 2017:3; UN High Commissioner for Human Rights, 2017):

*“...persons with mental health conditions are the foremost experts in their own recovery and in assisting others in their recovery. Peer workers provide each other with support and a sense of belonging, in addition to their expertise, thus reducing unnecessary admissions, and their use is central to mental health care”* (WHO, 2013).

Hence, a dialogue between personal experience-based and professional-based knowledge, practice and perspectives is of utmost importance (Boevink, 2017). If rooted in the recovery theory and human rights based approach, these services do have a potential to shift the currently still very much institutional culture within them towards a more inclusive and effective community-based service provision. This does go back to the systemic challenges, as in order for this to be achieved, the State also has a role by which to ensure the availability of recovery and human rights based support in the community (UN High Commissioner for Human Rights, 2017).

## Conclusion and Recommendations

In the broader systemic context of Lithuania's obligation to implement the principles and direction of the UN CRPD in its national legislation, policy, action plans, programmes and practices, this study of quality of care and human rights conditions in two Municipal 'Independent Living Homes' in Vilnius has conclusions on two parallel levels. One is the facility-based level and the other one is system-based. Both the good practices, as well as gaps in these services' provision have been identified by the study. Moreover, the study has discovered deeply-rooted systemic issues that surround and restrict the current and potentially the future development, effective delivery and improvement of community-based services for persons, who have mental health problems, intellectual and/or psychosocial disabilities.

In its current state, the two studied 'Independent Living Homes' were assessed to have some positive features and practices; however, improvements are needed in all five thematic areas explored by this study. The right to an adequate standard of living was discovered to be ensured mostly on the physical and material levels; however, gaps were identified in practice related to the lack of human rights based approach and recovery oriented models of support provided in the two facilities. Investment in professional development of staff is lacking, which creates obstacles for a more effective services' provision. The right to the highest attainable standard of *physical health* is mostly ensured in both facilities; however, that of *mental health* is more complicated, neglected and left behind. None of the service users are deprived of their legal capacity; however, neither supported decision-making nor use of advance directives are employed in either of the two facilities. In the most severe cases, especially in cases of fights taking place amongst service users, the staff of both facilities call the police or ambulance and the person receives all the necessary treatment. However, none of the staff are trained on alternatives for seclusion or restraint, nor on de-escalation techniques that would help to avoid any harm being done to both service users and staff themselves. The right to live in the community is initiated in both facilities; however, they still display a lot of features of institutional culture and staff demonstrate bio-medical model based attitudes to mental health.

All of the above is surrounded by deeply-rooted systemic issues and challenges, related to every single thematic area addressed by this study, which need to be addressed in a complex and comprehensive way. The results of this study suggest that there is a great need to critically review the current direction of the deinstitutionalization in Lithuania. It is crucial to ensure its compliance with the international human rights standards and evidence-based best practices.

### ***Facility–Level Recommendations***

- To provide the 'Independent Living Homes' services in a way that would create and provide a piece of a chain or a pathway for service users to eventually move to live more independently in the community. A segregated and specialised facility, in which around 30 persons, who have disabilities, reside under one roof, is unlikely to ever become a

place that people could call ‘home’ in its true meaning. Such a service could potentially be a ‘stepping stone’ but not the final destination for people.

- To invest in staff training and facilities’ policy development around the alternatives to seclusion and restraint, and de-escalation techniques for intervening in crises and preventing harm to self and/or others, as well as anger management.
- To invest in staff training, including social work assistants and duty guards. Knowledge and skills development in such areas and topics as mental health first aid, recovery theory, human rights based approach, personal assistance model, person-centred approach, case management, supported decision making, and UN CRPD in general are highly recommended.
- To ensure that any practices, such as taking away and storing service users’ passports, bank cards and/or other personal belongings, is only ever done with a full and informed consent of the person. Such instances should be thoroughly documented according to national laws and regulations.
- To ensure that the buildings of the facilities are adequately accessible for persons, who have mobility problems or physical disabilities; especially, around the emergency and fire exits, as well as access to leisure rooms and common areas of the facilities.
- To review and improve measures that are in place to protect people against injury through fire: regular and comprehensive fire drills that involve not only staff but service users too, and stimulations of practical procedures that are to be taken in case of a real emergency are advised.
- To ensure that the ventilation systems and plumbing in the buildings are reviewed and upgraded in order to provide more comfort and better standard of living for the residents.
- To enable more choice and control over where and with whom service users live; also to consider reducing the number of residents sharing rooms-studio flats in order to increase the personal space that individuals have, storing space for their belongings, and also privacy levels of each person.
- To review visiting rules, where they are restricted, in order to respect the right to receive visitors, choose who one wants to see and participate in visits at any reasonable time.
- To improve the layout of the facilities as to make them more conducive to interaction between and among service users, staff and visitors.
- To pro-actively ensure a range of person-centred, regularly scheduled, organized activities in both facilities, but more importantly – in mainstream community settings. To provide information to service users about activities in the community and pro-actively facilitate their access to those activities.
- To integrate Advance Directives and supported decision-making in the usual practices and ways of support provided.
- To eliminate the existing power imbalances between service users and staff, paternalistic and disrespectful attitudes, as well as the remaining features of institutional culture displayed in both facilities.
- To enhance service users’ access to legal representatives and related support in cases when this is needed.
- To seek regular monitoring by an *independent* authority to prevent the occurrence of potential abuse and ill-treatment in both facilities.

## ***System–Level Recommendations***

- To review deeply-rooted systemic issues that surround and restrict the current and potentially the future development, effective delivery and improvement of community-based services for the most vulnerable individuals in our society.
- To critically review the current direction of the deinstitutionalization in Lithuania in order to ensure its compliance with the international human rights standards and evidence-based best practices.
- To truly involve persons, who have mental health problems, intellectual and/or psychosocial disabilities, as well as their families, and representing organizations, in all stages of such a review, planning for the future of community-based support and services in the country, and eventual evaluation of the effectiveness of such services’.
- To ensure regular and comprehensive inter-sectoral collaboration between the Ministry of Social Security and Labour, Ministry of Health, Municipalities and other key stakeholders, such as the academia and non-governmental organizations. This is especially relevant in the context of the ongoing deinstitutionalization and development of new methodologies for community-based services, currently coordinated by the Ministry of Social Security and Labour.
- To fully align the national mental health and social care policy and legal framework with human rights standards and the UN CRPD, as well as with the principles of the Agenda 2030 for Sustainable Development; develop and implement human rights based strategies and plans in the field of mental health, and share technical expertise and other resources, such as good practice examples.
- To address the imbalances in society’s attitudes to mental health and related services; to ensure the shift towards a more comprehensive bio-psychosocial approach instead of the predominant bio-medical one, deeply rooted in institutional culture.
- To increase public awareness of human rights in mental health and disability related matters; reduce and eliminate related stigma and discrimination.
- To ensure realization of the right of everyone to legal capacity, and mainstream supported decision-making, as well as other evidence-based best practices.
- To ensure the legal requirement for mechanisms for regular monitoring of any specialised community-based services by an *independent* authority to prevent the potential occurrence of ill-treatment, abuse, and other human rights violations.
- To take measures in order to make mainstream services accessible to persons who have mental health problems, intellectual and/or psychosocial disabilities.
- To ensure continuous research and evaluation in order to ensure the most effective and human rights based development, as well as better social care and health outcomes, as a result of the deinstitutionalization of mental health services in the country.

## ***Recommendations for Further Research***

A broad and comprehensive study of evidence-based international best practice examples and their adaptability in the Lithuanian context could provide a solid foundation for the most effective deinstitutionalization and development of community-based services in the country.

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# The Deinstitutionalization of Lithuanian Mental Health Services in Light of the Evidence-based Practice and Principles of Global Mental Health

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**Abstract.** *During this time, in which Lithuania is going through the deinstitutionalization of its mental health services, the principles of Global Mental Health are especially relevant. This global field for study, research and practice places a priority on improving mental health outcomes as well as reducing respective inequities for all people worldwide. Scaling-up support services for persons who have mental health problems based on both scientific evidence and human rights has become one of the main focuses for action globally, and the key principles of Global Mental Health apply to the situation in Lithuania as much as they do in a number of other countries. This article explores the critical need to effectively reform the existing mental health care system in the country, which in its current form often results in human rights violations. It points to the idea, based on the global evidence base, that different Lithuanian authorities and other key stakeholders could start working together in an intersectoral way in order to reorganize mental health services from institutional to community-based models of care. It is suggested by this article that a sensible, local application of the broad key principles of Global Mental Health could be a mature and rational step taken by Lithuania. This has the potential to be a major step toward the improvement of human rights and mental health outcomes in the country.*

**Keywords:** *Mental health, human rights, deinstitutionalization.*

## Introduction

The World Health Organization's (WHO) World Mental Health Survey has demonstrated that even though less prevalent than physical disorders, mental health problems and related conditions lead to higher rates of disability (Caldas de Almeida et al. 2013). Additionally, the "days out of role" due to mental health problems are a major source of lost human capital (Alonso et al. 2011). Hence, the effects of mental health problems and related disability result

in having an impact not only on the quality of life of individuals themselves, their families and communities, but also extend to affect the economics of countries and employment rates, which further impact other related policies (Wang et al. 2011).

However, the prevalence of mental health problems, as proven by multiple epidemiological studies, far surpasses the availability of *specialist treatment* services, even despite the detrimental manifold effect this has on a population. Moreover, there are studies consistently showing better outcomes worldwide in *community-based* services for individuals who have mental health problems or psychosocial disability. These studies show greater accessibility to care, protection of human rights, prevention of stigma (Thornicroft and Tansella 2003) and greater user satisfaction (Thornicroft and Tansella 2003; Killaspy 2007) when compared with other models of support, e.g., institutional care. According to Patel and Prince (2010), as an area for study, research and practice, Global Mental Health places a priority on improving mental health, related care and support availability and outcomes as well as on reducing respective inequities for all people worldwide. Generally, the Movement for Global Mental Health is described as a network of persons and institutions committed to close the significant treatment gap (Patel and Prince 2010).

The outdated and human rights violating mental health care system, rooted in institutional culture, one that perpetuates stigma, social exclusion, isolation, segregation and discrimination still exists in Lithuania, as it does in many other countries across the globe. The actual *implementation* of the country's modern Mental Health Strategy (2007), the action plan and its related programs are currently ineffective (Puras et al. 2013). Major efforts are required in order to generate political commitment and support for this matter. Currently expressed political, institutional and budgetary commitment, as per concepts described by Caldas de Almeida et al. (2013), is lacking in Lithuania and "most of the measures [in the action plan] are not carried out or their implementation is constantly being postponed" (Puras et al. 2013).

Continuous research and evaluation are essential in order to ensure not only the most effective development, which would be based on human rights, too, but also the improvement of mental health care, treatment, support and respective services (Hanlon et al. 2010). Thus, the aim of this article is to identify how the key principles and approaches of Global Mental Health could be applied to the local context, aiming to pursue the urgently needed effective reform and reorganization of the Lithuanian mental health care system and services. The objectives of this article are as follows: to present the background of Global Mental Health and its related worldwide movement; to identify the relevance that Global Mental Health bears on the local context in Lithuania and how the ongoing deinstitutionalization in Lithuania actually relates to the identified global principles; to discuss the experience of the development of community based services worldwide and what could be learnt from this experience; to analyze the existing evidence base for the globally identified common barriers and strategies for overcoming those in relation to the deinstitutionalization of mental health services; to draw recommendations for further academic research, as well as to the decision-makers on the more

practical level, for the potential ways forward in developing more effective mental health services and achieving better outcomes of mental health and human rights in Lithuania.

### **Methodology of the Analysis**

The author of this article has reviewed, analyzed and related to the current local context of Lithuania a number of existing international scientific publications and best practice examples in the field of Global Mental Health. This has been completed in conjunction with the author's personal and professional experience obtained through her day-to-day practice in the non-governmental sector as well as over ten years of international working experience in the field of mental health in general. The knowledge and evidence base provided by the analysis of scientific publications and best practice examples from across the globe has enabled the author to discuss the relevance of the aims, principles and outcomes of Global Mental Health to the current local context in Lithuania. It has allowed for the analysis of the ongoing deinstitutionalization and its effectiveness, from the perspective of these principles, and for drawing of specific recommendations for the potential ways forward in order to achieve better human rights and mental health outcomes in Lithuania. This is especially relevant in the light of the existing and presently stagnant post-Soviet mental health care system and the ongoing reform of the often-human-rights-violating mental health services in the country.

### ***The Concept of Global Mental Health***

Global Mental Health may be described as an area for study, research and practice that places a priority on improving mental health, related care and support outcomes as well as reducing respective inequities for all people worldwide (Patel and Prince 2010). The main principles of it address are such global inequities in the mental health field as gaps in care, treatment and support provision as well as prevalent human rights violations of persons who have mental health problems and who often suffer from poor quality of life, stigma and discrimination. The ultimate goal of Global Mental Health is to improve the quality of lives of individuals, through looking for a better understanding of the origins and causes of mental health problems and conditions, as well as to search for effective and affordable treatments, care and support. Patel and Prince (2010) argue that scaling-up services for persons, who have mental health problems or psychosocial disability, on the twin-principle of scientific evidence and human rights has become one of the main focuses for action within Global Mental Health.

In addition to the above, Patel and Prince (2010) describe the movement for Global Mental Health as a “coalition of individuals and institutions committed to close the treatment gap.” According to Kohn et al. (2004), the treatment gap in mental health provides that even though mental health problems are highly prevalent worldwide, there is a significantly large number of persons who have those remain untreated even though effective treatments and other types of support do exist. According to WHO, the treatment gap for severe mental health conditions has been between 35–50% in developed countries and between 76–85% in low- and middle income countries (WHO World Mental Health Consortium 2004). Patel (2016) argues: “Given the limited knowledge that we currently possess about the nature of mental disorders

or their effective prevention and treatment, this may well be the most important ultimate contribution of global mental health, i.e. generating knowledge which not only reduces the treatment gap, but the actual global burden of mental disorders, and will finally do justice to the ‘global’ of this discipline.” Becker and Kleinman (2013) identify a number of major initiatives in Global Mental Health, which include the following:

- Mental Health and Poverty Project and the Programme for Improving Mental Health Care, both supported by the Department for International Development in the UK;
- The Grand Challenges Canada program;
- Grand Challenges in Global Mental Health, led by the National Institute of Mental Health and the Global Alliance for Chronic Disease, in partnership with others.

Additionally, several “milestones” are described by Becker and Kleinman (2013) that mark significant advances in the integration of mental health care into primary health care in settings with constrained resources worldwide:

- World Health Report devoted to mental health in 2001, preceded by World Mental Health, Harvard (1995) and WHO Nations for Mental Health (1996);
- Mental Health Global Action Programme (mhGAP) in 2002;
- Series of reviews published in 2009, providing recommendations on a model of collaborative care (Patel and Thornicroft 2009; Patel et al. 2009);
- WHO mhGAP and Global Movement for Mental Health (2009); mhGAP Intervention Guide (2010); WHO training package (2012).

The more country-specific initiatives noteworthy for their measure of early success identified by Becker and Kleinman (2013) are as follows: an integrated approach to scaling-up equitable care for poor populations in Kenya (Kiima and Jenkins 2010) and integrating mental health into health sector reforms in Egypt (Jenkins et al. 2010). Additionally, due to various policy and legislative efforts and initiatives, “successful and innovative reform processes have taken place in most Latin American and Caribbean countries” (Caldas de Almeida and Horvitz-Lennon 2010).

Finally, the shift in Global Mental Health to a collaborative model of care delivery is also significant. The ‘*task-shifting*’ model focuses on the mental health specialist as having a reconfigured role, emphasizing training, supervision and tertiary care, “while transferring the bulk of direct service delivery to community health workers or primary care professionals, who would receive specific training and supervision in mental health” (Patel 2009). A human resources gap could potentially be reduced through “task-shifting” (Petersen et al. 2011), which is an “evidence based approach to addressing the human resources challenges to scaling-up effective treatments” for mental health problems (Patel 2009).

The following analysis employs the main messages and principles of Global Mental Health as a prism through which the author looks at how the ongoing mental health services’ reform in Lithuania meets global standards; how effective or ineffective its deinstitutionalization of mental health services has been so far; finally, how could one of the main pillars of successful

deinstitutionalization – the development of community-based services – be improved, based on the global evidence base and best practice examples.

## **Analysis**

### ***Applying Global Mental Health Principles and Approaches to the Lithuanian Context***

The main principles of Global Mental Health that may be described as specifically relevant to the current Lithuanian context are as follows: 1) The acknowledgement of gaps in mental health care, treatment and support provision; 2) The search for and promotion of effective and affordable treatments, care and support, and scaling-up of community-based services; 3) Respect for fundamental human rights of all persons; 4) The fostering of the best possible quality of life for individuals through looking for a better understanding of the origins and causes of mental health problems and psychosocial disability; 5) The reduction of stigma and discrimination against persons who have mental health problems or psychosocial disability.

According to Puras et al. (2013), the situation in Lithuania is very complicated when it comes to an official acknowledgement of the system as being ineffective and as having serious gaps. It is evident that instead of accepting this fact and solving the existing problems in a mature way, currently, the stagnant system is being strengthened even further. This, in its turn, only deepens segregation, stigma, social isolation and exclusion. Up until this day, human rights monitoring in healthcare facilities is very rarely applied; there is not one independent monitoring body in the country, which would be responsible for the rights of patients, related control, addressing of complaints, independent analysis of the broader situation, monitoring of legislation review and human rights in this specific field in general (Puras et al. 2013). Such key issues as policy development versus services organization and policy implementation could be seen as central to the current situation of mental health care and services in Lithuania. However, it appears that any processes of change in the existing post-Soviet mental health care system are often hindered by the lack of top-down *and* bottom-up initiatives working *together*. Additionally, such key messages of Global Mental Health as the resources to treat and prevent mental health problems remaining insufficient, inequitably distributed and inefficiently utilized may be seen to apply to the situation in Lithuania, as much as they do in many other countries.

Even though compelling arguments have been made globally to advocate for the investment in mental health services as being “a matter of cost-effectiveness, social justice, and even a smart development strategy” (WHO 2010: 2; Lund et al. 2011), the political commitment to mental health care in Lithuania has not been reported to strengthen much thus far. The tangible and effective implementation of the National Mental Health Strategy (2007), action plan and related programs is almost non-existent (Puras et al. 2013); this indicates that both expressed political, institutional and budgetary commitment, as well as inter-sectoral collaboration, are majorly lacking. Hence, the strong prioritizing of better mental health outcomes and scaling-up of effective services on the principles of scientific evidence and human rights (Lancet Global Mental Health Group 2007) have thus far been significantly delayed in the Lithuanian context.

The outline of the present local situation and arguments, summarized in the two paragraphs above, illustrate the clear divergence from the first two principles of Global Mental Health. It points to the abstention from acknowledging the gaps in provision of mental health care in the first place and then points to this being complemented by the lack of active search for and promotion of effective and affordable treatments, care and support, as well as of scaling-up of services, based on scientific evidence and human rights.

Nevertheless, a *partial* scaling-up of mental health services may be observed to have in fact taken two distinct paths in Lithuania. According to WHO and Wonca (2008), it is important to integrate mental health into primary health care in order to achieve truly holistic care for all people, additionally integrating mental health care into other existing health programs. This type of *integration* has indeed started in Lithuania: Puras et al. (2013) describes clear developments in the field from as early as 1999, when the State Mental Health Centre was established. This landmark had a strategic meaning and was at the time surrounded by such other developments as the Government adopting the Program for the Maintenance of Mental Disorders (1999–2009). This Program described the plans for improving the accessibility of mental health services in primary, secondary and tertiary levels of healthcare. Additionally, the National Mental Health Committee was established in 2000, which was assigned the responsibility for ensuring inter-sectoral collaboration in the field of mental health policy. However, according to Povilaitis et al. (2015), in practice, all outpatient mental health services in Lithuania are currently provided either by the General Practitioners, or at Mental Health Centers, which are mostly a part of the primary healthcare level. It is argued by Povilaitis et al. (2015) that, in following a thorough analysis of the services provided at Mental Health Centers, it is clear that it is dominated by the biomedical model and treatments are based on providing medications: this type of treatment is currently reported to be the most accessible to all. Additionally, Murauskienė et al. (2013) argues: “Because of the large flow of patients with mild disorders to the mental health centres and lack of resources (including the staff numbers and skill mix), interventions are commonly limited to a short consultation with a psychiatrist and administration of medicines.” Meanwhile, psychologist consultations or psychotherapy are only accessible to around 4.33% of all persons who are registered as having mental health problems (Povilaitis et al. 2015).

All of the above indicates that the secondary mental health care level is practically non-existent and there are currently next to none effectively working community-based services, such as mobile outreach teams or psychosocial rehabilitation for people who have the more severe mental health problems or psychosocial disabilities. This points to serious gaps in the mental health services provision and a lack of effectiveness in the processes of the related national reform and deinstitutionalization of services, which again may be described as not compliant with the key principles of Global Mental Health.

According to Puras et al. (2013), even though the National Mental Health Strategy was adopted by the government of Lithuania in 2007, most of its measures have not been implemented. This may still be observed as being the case now in the year 2017, ten years

after the adoption of the Strategy. Once again, this indicates the significant lack of political will, among other factors. Additionally, the Lithuanian Action Plan (2014–2020) for the Transition from Institutional to Community-Based Care was approved by the Minister of Social Security and Labor on 14<sup>th</sup> February 2014. However, there are still no practically visible improvements within the existing post-Soviet style mental health care and support system in the country. Moreover, this Action Plan focuses only on the social care institutions, completely leaving out of the planned reform the psychiatric hospitals and any other medical facilities or systems. This is due to the medical facilities being a responsibility of the Ministry of Health, unlike the social care institutions that fall under the programs by the Ministry of Social Security and Labor. It appears to be inevitable that due to the lack of inter-sectoral collaboration, no synergies are currently being drawn between potentially reforming both systems in parallel with each other. This essentially may be described as going against the global principle that to be effective mental health services and systems have to be planned and managed in an inter-sectoral way (Petersen et al. 2011).

According to the Ministry of Social Security and Labor, there are regular queues of up to 200 people who wait to be admitted to social care institutions. This indicates that *noninstitutionalization* and adequate provision of acute, as well as continuing, mental health care and services closer to or in the communities where those affected live (Patel and Prince 2010) are still lacking in Lithuania, and people are forced to wait in queues in order to be admitted to institutional care instead. The existing permanent queues of people waiting to be placed into institutional care suggest that alternative forms of support have not been offered to them. This digression from effective implementation of the foreseen reforms clearly results in non-compliance with yet another fundamental principle of Global Mental Health – respect for human rights of all persons. The lack of and/or unavailability of community-based services inevitably determines subsequent human rights violations, especially those under Article 19 of UN Convention on the Rights of Persons with Disabilities, as well as restriction of choice and loss of dignity and autonomy. This permanent flow into institutional care may be assessed as contributing significantly to keeping the existing mental health care system stagnant and resistant to change, whilst programming itself for subsequent human rights violations, poor quality of life of service users, and restrictions of their participation and inclusion in society, which does not comply with most of the key principles of Global Mental Health.

Moreover, it is relevant to the Lithuanian situation, that, as stated by Becker and Kleinman (2013), “[...] the most basic cultural and moral barrier to the amelioration of global mental health problems continues to be the enormously negative, destructive, and almost universal stigma that is attached to mental illnesses, to patients with a mental illness and their families, and to mental health caregivers.” People with mental health problems do not tend to seek help, they struggle with their recovery and are often socially isolated in Lithuania, all due to high levels of stigma and discrimination linked to mental health and related disabilities (Murauskienė et al. 2013). Currently even in media there are plenty of publications that are discriminatory and which reinforce the stigma in the attitudes toward people who have mental health problems (Mataitytė-Diržienė 2011). From all of the above, it is clear that integration of such aspects as, for example, the modern “recovery approach” into the new models of



mental health services in Lithuania are currently rare. Potentially, such practices would mean finally moving closer to accepting that people who have mental health conditions “are central to their own recovery and can manage their mental health problems themselves, supported by family, friends and community” (Saraceno et al. 2015). The promotion of the recovery approach in Lithuania could potentially contribute to the improvement of care, support and quality of life of people who have mental health problems, and move Lithuania closer to complying with the principles of Global Mental Health, reducing stigma and discrimination, too. In its turn, this could also tap into achieving the collective goals and principles of Global Mental Health, aiming to improve the lives of individuals living with mental health problems all around the world (Patel and Prince 2010).

### ***Development of Community-Based Services Across the World***

The complex process of developing mental health services has been observed in three periods across the world: “the rise of the asylum, the decline of the asylum and the reform of mental health services” (Wing and Brown 1970; Grob 1991; Desjarlais et al. 1995; Thornicroft and Tansella 1999; Thornicroft and Tansella 2004). According to Thornicroft and Tansella (2004), currently there is no global consensus on which of the mental health service models are most appropriate in low, medium or high-income countries. Naturally, different mental health care models work in different areas of the world, depending on the level of available resources and other factors. For example, the provision of certain follow-up community services is more prevalent in upper-middle-income countries than in low-income countries (WHO-AIMS 2009). Nevertheless, nowadays there is an international consensus on the need “to shift from the model of care based on the traditional large psychiatric institutions to modern comprehensive community-based models of care, including acute patient units at general hospitals” (Caldas de Almeida and Killaspy 2011). Hence, there is a clear global call for deinstitutionalization of mental health services in all countries.

The common experience of barriers to mental health services’ reforms and shifting toward community-based care and support primarily in low- and middle-income countries presents a significant body of evidence and factors to consider for other countries, such as Lithuania, that are currently undergoing the deinstitutionalization. Saraceno et al. (2007) identifies that, first, the lack of political will evidently poses a great hindrance to any effective reform of mental health services in most countries. Secondly, the related advocacy is often not defined clearly enough, it is not targeted enough, nor empowering enough of the people who have mental health problems and their families themselves. Thirdly, the development of secondary care-level community-based services is often not prioritized. Finally, formal and informal resources, which are already available in the community, are often not used in effective and efficient ways by those developing and delivering community-based services. All the above describes several very clear and commonplace barriers, which are of relevance and are to be carefully considered by any country undergoing the deinstitutionalization and developing new community-based services that eventually are to replace all institutional care.

The development of community-based services globally has so far presented that any comprehensive changes in mental health services require provision, and that lasting

improvements take time to achieve and cannot be rushed (Thornicroft et al. 2008). This is due to various factors, such as the adjusting of the mental health staff to new ways of thinking and working, acceptance of change and them actually starting to believe that such changes can be positive and are likely to bring positive outcomes for the service users. According to Killaspy (2006), longer-term studies (Leff 1997; Leff and Trieman 2000; Trieman and Leff 2002; Thornicroft et al. 2005) of the outcomes that followed service users, who had spent a number of years living in asylums, and eventually moved to live in the community with appropriate support, have demonstrated that “[...] the majority of people, even those with the most complex problems, have increased their social networks, gained independent living skills, improved their quality of life and have not required re-admission.”

Additionally, support of not only staff but also of various organizations and agencies, including international actors, is important and also takes time to be ensured. It is to be identified and established gradually in order to succeed in achieving sustainable mental health services change. Moreover, as stated by Thornicroft et al. (2008), it is often necessary to build a wide political consensus on the national mental health strategy, so that when the government changes, it does not affect the consistency of striving for improvement of services. Finally, “time is also needed to progress from the initiation stage of a change to the consolidation phase” (Thornicroft et al. 2008). This is deemed important in order to ensure sustainability and long-term maintenance of any newly established systems and services.

With regards to the Lithuanian situation, in relation to the global evidence base described above, Puras et al. (2013) states that political will in the mental health policy field was demonstrated by the Minister of Health Ž. Padaiga back in 2005–2007; however, that did not grow into a wider political consensus and, up until now, the long-term strategic and coherent implementation of deinstitutionalization is missing in the country. This, in its turn, indicates that the possibility for Lithuania to use the best global practice examples and evidence with regards to development and implementing of new community-based services for people who have mental health problems or psychosocial disability is still hindered and restricted.

Moreover, hearing the voices and valuing the expertise of service users and their families is seen as being vital across the world. This is a unique expertise, gained through direct experience and perspectives of people. Since the ultimate aim of services’ improvement is to improve the quality of life of the service users and their families/carers, so it is important that their voices, choices and advice are sought, taken into account and valued immensely. This is still observed as lacking in Lithuania, where the “expert” label is often given to the medical professionals and personnel of service providers instead of the service users. Ruškus and Mažeikis (2007) argue that especially within the “clinical vision,” more emphasis is put on the person’s problems and inabilities, rather than on the valuing of his/her potential and expertise. It is then inevitable that whilst being surrounded by such negative predominant approaches, the voices of service users and their families can hardly be truly heard and valued.

Another aspect of development of community-based services worldwide has been related to economics, finance and budget-planning. It refers to the fact that the team managing the

process of change in service provision is deemed to need “clear expertise to manage the whole budget and that the risks are high that services changes will be used as an occasion for budget cuts” (Thornicroft et al. 2008). Commonly, additional funding is required during the transitional period, which naturally poses a significant challenge, especially in low- and middle-income countries (Saraceno et al. 2007). Due to various reasons, including the lack of political will, such an additional funding has not been identified thus far in Lithuania, and one of the main arguments for the slow deinstitutionalization by the government officials is often based on the perceived myth of there being not enough money within the system required for financing the related processes.

Over the years it has also been assessed globally that there is no scientific evidence to say that either hospital services *alone* or community services *alone* can ensure most effective, satisfactory and comprehensive mental health care. Instead a “balanced approach,” with elements of both hospital and community care, has been supported by both the evidence and practical experience (Thornicroft and Tansella 2002). As described by Thornicroft and Tansella (2004), the balanced approach framework can be applied differently in settings with different levels of resources, through the “stepped care model.” For example, the balanced approach in countries with low levels of resources may include improving primary mental health care, with only a specialist back-up, whereas countries with medium resources may additionally aim to provide “out-patient clinics, community mental health teams, acute in-patient care, community residential care and forms of employment and occupation” (Thornicroft and Tansella, 2004). However, according to Thornicroft and Tansella (2004), the stepped care model does raise a couple of significant challenges and implications, as follows. First, to work most effectively, the model requires a well coordinated system with an adequate and often multidisciplinary management of the provision of primary and specialist care. Second, the model implies that the level or resources and training of mental health professionals needs to be adequate to the service stage that has been reached. Realistically, this points to the risk that it may cause gaps in practice, which in turn might seriously affect local planning and development of quality services; hence, it requires an in-depth prior analysis, consideration and strategic approach.

In general, development of community-based services in most countries is a lengthy and complex process (Thornicroft et al. 2008) that faces several challenges and barriers, and Lithuania is no exception here. These barriers include some that exist at the policy level, and others at the level of the existing health care system (WHO World Health Report 2001). For example, these could include competing priorities, lack of inter-sectoral collaboration, underfunding, negative attitudes toward mental health and concerns about skills of staff and quality of care (Hanlon et al. 2010). Moreover, during the deinstitutionalization and development of community-based services, all of the main areas of people’s lives need to be effectively addressed, as described by Rossler (2006). For example, for the *housing* part of individuals, who will eventually be leaving psychiatric hospitals and social care institutions during deinstitutionalization, the flexible and individualized *supported housing* option has been proven to be mostly effective worldwide. Rehabilitation research shows that “once in supported housing, the majority stay in housing and are less likely to become hospitalised”

(Rossler, 2006). With regards to *education and employment*, it is now common knowledge, backed up by science, that engaging in work has positive effects on mental health. It has been proven to have the potential for people to achieve improved cognition, quality of life and better symptom control through engaging in meaningful work activities. Additionally, the most promising vocational rehabilitation model today is believed to be *supported employment*. In addition to the above, the *social skills* training also has an important role to play in psychosocial rehabilitation and deinstitutionalization: “social and community functioning improve when the trained skills are relevant for the patient’s daily life and the environment perceives and reinforces the changed behavior” (Rossler 2006). Finally, Rossler (2006) states that the role of a psychiatrist, integrated in a community team, is also important as an integral part of the multidisciplinary support to the individuals, especially those with persistent, long-term mental health problems and conditions. All the above demonstrates how complex and inter-sectoral the processes of deinstitutionalization are and how much systemic planning and collaboration between different key stakeholders it requires.

Since differences in mental health services between low-, middle- and high-resource countries are vast (Thorncroft and Tansella 2004), the *strategies* that could be adopted to address the related challenges also vary from country to country. The resources (un)available in a country will severely constrain how the “balanced approach” and “stepped care model” are applied in practice (Thorncroft and Tansella 2004), and this is relevant in the Lithuanian context, too. However, regardless of the area, the planning and decision making are always to be informed by such elements as ethics, evidence and experience (Thorncroft et al. 2008), and include both community and hospital services (Thorncroft and Tansella 2004). Also, the planning and investment of funds in mental health care worldwide have included a wide range of stakeholders, amongst them service users and family members/carers, participating in related decision making. Building coalitions of stakeholders to oversee the scaling-up of balanced care, as well as including advocacy for sustainable resources, engaging with other relevant health and non-health programs to truly integrate mental health in their activities and raising awareness about mental health, as well as human rights, are all likely to prove as effective strategies in the strive for change in any country.

Mostly low-income countries have been found to be likely to more effectively provide mental health services in the primary healthcare level with specialist supervision, training and backup (Mubbashar 1999; Saxena and Maulik 2003). Redefining the role of specialists, in general, “is essential to reforming mental health services in low-income and middle-income countries, and will require specialists to be trained in adult-learning methods to train and supervise others” (Saraceno et al. 2007). This is especially relevant in the Lithuanian context, even though it is deemed to be a high-income country, nevertheless, the specialist psychiatric community play a significant role in the mental health services planning and provision. Additionally, according to the global evidence base, the development of robust mechanisms to ensure reliable supplies and availability of essential psychotropic medications is also needed, which would be in balance with basic and “feasible psychosocial interventions to augment medication approaches in the time-pressed primary care setting” (Hanlon et al. 2010).

### ***Deinstitutionalisation: Common Barriers and Strategies for Overcoming Those***

As per the contextual analysis presented in the chapters above, the gaps in the mental health care system in Lithuania include the following: inaccessibility, inadequately used resources, a lack of new investments, an old post-Soviet infrastructure of services, a lack of preventative measures, prevailing stigma and discrimination as well as the bio-medical approach, a lack of individualized support, little acknowledgement of social determinants of mental health, often low quality of care and violations of human rights (Puras et al. 2013). At least three main specific barriers to effective progress in improvement of mental health services that are relevant in the current context of the country, may be defined. Based on the globally established evidence base, these barriers to improvement of mental health services in Lithuania and the potential comprehensive strategies for overcoming them are described and looked at below.

#### ***Centralised Mental Health Resources, Mostly in Large State Residential Social Care Institutions and Psychiatric Hospitals***

A smooth transition to decentralized, community-based services in Lithuania could be aided by a reallocation of existing funds as well as some additional funding during the transitional period: both of which are currently lacking. Such means would be required from both the Ministry of Social Security and Labor, responsible for social care institutions, and the Ministry of Health, overseeing psychiatric hospitals. Additionally, municipalities also play an important role here in Lithuania, especially when it comes to development and funding of community-based services. Unfortunately, as it is common globally, so too in Lithuania the main decision makers have “the incorrect perception that mental health care is not cost-effective” (Saraceno et al. 2007), thus investment in this area is scarce. In many countries, including Lithuania, “scarce mental health funds are spent on long-term institutional care [...] and on [...] pharmaceuticals which, in general, are much less cost-effective than community-based care and generic essential medicines” (Saraceno et al. 2007; WHO 2006; Hyman et al. 2006). Not only does institutional care generally consume most of mental health resources, it also contributes to the social isolation of individuals from their natural support systems and creates opportunities for human rights violations and societal stigma (Saraceno et al. 2007), which in itself is a major public health concern (Saraceno et al. 2009). Reforms of institutional care-based mental health care systems commonly tend to be hindered by a lack of development of community-based services (Saraceno et al. 2007), and this too may currently be observed to be the case in Lithuania.

As it also has been observed by Saraceno et al. (2007) in other countries, one of the key barriers to progress in the decentralization of mental health services in Lithuania has been the resistance by mental health workers, whose interests are served directly by the existence of large social care homes and psychiatric hospitals. Feelings of insecurity are reported to be prevalent among them, they are anxious about losing their jobs and do not have adequate information about the reform; hence, they are reluctant to contribute to it and avoid accelerating the “undesirable changes” in any way (Sumskiene et al. 2015).

Generally, the psychiatric community and management of social care institutions tend to have the power over most of the mental health system-related decisions in Lithuania. For example, the heads of social care institutions are the main invited members of inter-ministerial working groups for deinstitutionalization; the Regional Development Councils are responsible for overseeing related processes in the regions. Hence, the main responsibility for planning and implementing the reform lies with the persons who have an obvious conflict of interests, a desire to sustain their own social care institutions, and, at the same time, often lack the knowledge of human rights based approaches and competences for the development of community-based, individualized and person-centred services (Sumskiene et al. 2015).

### ***Difficulties in Integrating Mental Health Care in Primary Health Care Services***

A recent analysis of mental health services at the primary health care level shows that currently, the primary-care Mental Health Centers in Lithuania predominately provide pharmaceutical treatment, mostly due to its accessibility and the predominant biomedical approach. Meanwhile, counselling, psychologist consultations and/or psychotherapy are only accessible to about 4.33% of people who have mental health conditions (Povilaitis et al. 2015). The assigned functions of Mental Health Centers are seen by experts in the field as needing a review in order to ensure real opportunities for the provision of preventative as well as clinical services, especially if having in mind the Mental Health Centers' extremely limited amounts of human resources (Povilaitis et al. 2015). For example, re-arranging the profile and structure of the existing Mental Health Centers across Lithuania to turn them into comprehensive and truly community-based and person-centred units, from which new *outreach services* and *home-visiting mobile teams* would operate, whilst redirecting mental health *prevention and promotion* functions to Public Health Centers, could potentially be a starting point. Then, at the same time, a network of psychiatric units available inside of the general hospitals could be established (Caldas de Almeida and Killaspy 2011).

Moreover, effective psychosocial rehabilitation programs are reported to be lacking both inside and outside of the psychiatric, as well as general hospitals, which could otherwise help to prepare people for living in the community (Caldas de Almeida and Killaspy 2011). According to Rossler (2006), all people who have severe mental health conditions require "psychiatric rehabilitation"; however, in practice, the Ministry of Health of Lithuania currently does not appear to follow the global advice to take a "balanced approach" or to focus on the two intervention strategies described below while addressing the needs of individuals during the future deinstitutionalization of psychiatric hospitals in Lithuania.

Rossler (2006) describes that most individuals would benefit from the empowerment to live in a community through the combination of the following two strategies: 1) An individual-centred strategy that aims at developing the person's skills in interacting with a stressful environment; 2) An ecological strategy directed toward developing the environmental resources to reduce the potential stressors. In "psychiatric rehabilitation" the real-life situations and conditions are to be taken into consideration whilst preparing individuals for leaving long-term psychiatric hospitals and prepare for the daily living situations that they are likely to encounter when living in the community (Rossler 2006). Additionally, time and

attention needs to be devoted to ascertaining personal goals, focusing on the person's strengths, with associated costs and benefits to those goals. In order to effectively coordinate and integrate all the different required services and professionals involved concentrating on different aspects of the same person, *case management* could be introduced and act as the key coordinating and integrating mechanism: "The core elements of case management are the assessment of patient needs, the development of comprehensive service plans for the patients and the arrangement of service delivery" (Rossler 2006).

The above described approaches are relevant to the Lithuanian context; nevertheless, currently, the deinstitutionalization of psychiatric hospitals and integration of mental health care into general hospitals or generic primary healthcare in Lithuania is reported not only to be slow but mostly not adequately happening in practice at all (Puras et al. 2013).

### ***A Lack of Political Will and Thus Funding for the More Effective Mental Health Care and Support***

This issue may be seen in some countries as partially affected by inconsistent mental health advocacy; the concepts used by advocates are often unclear to the policy/decision-makers. In Lithuania, this is especially relevant ever since the mass emigration started, following the country joining the European Union in 2004. Several years later, people started bringing back to Lithuania more and more new modern and global ideas, based on foreign experiences and concepts. Moreover, the confusion in understanding and advocating for the modern mental health principles has been even more pronounced ever since the ratification of the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol on 27<sup>th</sup> May 2010, the vision and direction of which differs from previously long-established national laws and predominantly post-Soviet and biomedical approaches. Such lack of clarity may also partially be due to there being "many types of mental health problems, advocates for mental health often lobby against one another to draw attention to different mental health problems, [...] each of which might need different *public mental health* solutions" (Saraceno et al. 2007). In Lithuania, this may be observed to extend to an additional element of strong competition among the leading mental health experts and non-governmental organizations (NGOs): due to scarce resources and small size of the country, they tend to compete for limited funding, human and other resources; hence, unfortunately, certain related disagreements may often literally be down to a "fight for survival."

In addition to the above, generally, it is relevant that people who have mental health problems and their families "in [...] middle-income countries are only rarely mobilised to form powerful constituencies, and to press for the availability of effective and humane mental health care" (Saraceno et al. 2007). In Lithuania, too, even though it is now classed by The World Bank as a high-income country, people who have mental health problems, their families and/or carers are often invisible, "voiceless", experiencing shame, discrimination and stigma. It is even challenging to engage service users and families in interviews for research purposes: people do not feel comfortable or willing to share their stories, even anonymously and with all the appropriate confidentiality measures in place (Grigaite 2014). Moreover, residents of social care institutions are rarely adequately informed about the potential changes

in the mental health care and support system; hence, they end up isolated and denied the opportunity to take an active part in the reforms. In fact, most often they are misinformed, for example, “residents of one [visited] social care institution have been informed that following the reform they will be accommodated in a new building, or vice versa, that they all will be released from the institution” (Sumskiene et al. 2015). This naturally leads to heightened anxiety among service users, consistent lack of self-advocacy and resistance to changes, which they just literally do not understand.

### ***Potential Strategies for Overcoming the Barriers***

There is more and more compelling evidence globally for prioritizing mental health (Saraceno et al. 2009). Saraceno et al. (2007) argues that it is important to generate political will in order to overcome the barriers to progress in improvement of mental health services. In order to generate political will for prioritizing mental health specifically in Lithuania, first of all, a consensus may be assessed to be needed between mental health and human rights advocates; the objectives and terminology of mental health advocacy to be more clearly defined, making it more focused and informative; also, more service users and their families/carers could be empowered to self-advocate.

Mental health advocates in Lithuania mostly work with the Ministry of Health, Ministry of Social Security and Labor, Ministry of Education and Science and the municipalities. However, inter-sectoral communication and collaboration between these various central and local authorities is still reported to be lacking and is consistently advocated for by local NGOs. Critical areas in service-planning that are deemed to need addressing by the Lithuanian policy/decision-makers in the light of best practices known in Global Mental Health are as follows: the downsizing of psychiatric hospitals and development of primary and secondary level mental health care; the integration of mental health into general hospitals; the development and provision of community-based services; the development and promotion of psychosocial rehabilitation. Trying to achieve this could potentially take a major shift in the prevailing paradigms, especially the one from the biomedical to biopsychosocial approach, with a focus on the social determinants of mental health, social and psychological dimensions of care and support. This would naturally require an inter-sectoral collaboration between all the respective authorities and other key stakeholders.

With regards to the primary mental health care level, the document governing the assigned functions of primary-care Mental Health Centers in Lithuania defines such services as prevention, treatment and rehabilitation. However, the volume and type of most such interventions are not reflected in the national statistics related to persons who have mental health problems or psychosocial disability (Povilaitis et al. 2015). Certain functions of the Mental Health Centers could potentially be delegated to other bodies; for example, activities related to mental health promotion and prevention could be transferred to Public Health Centers, since a key aim of any public health body is to “prevent disease/disorder wherever possible and to promote good health” (Saraceno et al. 2009). Also, the availability of and accessibility to quality counselling, psychological consultations and psychotherapy are



continuously advocated for local use (Povilaitis et al. 2015) and could be scaled up as per principles of Global Mental Health.

Additionally, the development of secondary care-level community mental health services has not yet become a priority on Lithuania's political agenda. "Decentralisation of services and integration of mental health into general health care are critical to improve mental health status in populations" (Saraceno et al. 2009). Downsizing both of social care institutions and of psychiatric hospitals would require availability of a wide spectrum of community-based services. Moreover, formal and informal resources that already exist within the community could be used more effectively: "[...] more action is needed to ensure that non-professional community members take part in mental health programming" (Saraceno et al. 2007). At the same time, it is argued globally that nonetheless, investment in primary care or existing tertiary care is vital, but *only* as long as it is "preceded by, or [...] at least in tandem with, development of community mental health services" (Saraceno et al. 2007).

In the case of Lithuania, evidently most of the European Union structural funding in 2007–2013 was used for the improvement of living conditions in social care institutions but without the tangible parallel development of alternative community-based services. In the next programming period of the European Union structural funds, an investment into development of community-based services in Lithuania is expected by local NGOs and activists, in order to overcome the barriers to improvement of the mental health care system, and specifically to decentralise mental health services.

Finally, "a set of simple, consensus-based indicators [need to] be monitored to track the progress of countries towards attainment of specific targets" (Lancet Global Mental Health Group 2007). However, the monitoring of the reform and development of new community-based services, and related indicators are currently reported to be insufficient in Lithuania: according to experts in the field, various indicators are currently missing, especially for monitoring of the progress of integration of mental health into primary health care services and the decentralization of mental health services (Puras et al. 2013). It was suggested by Sumskiene et al. (2015) that an accurate tracking of real changes in the number of beds in social care institutions and psychiatric hospitals could be an important indicator to be observed: "Along with other indicators of development of community-based services, it is important to assess this number every year to monitor the pace of the transitional processes."

## **Conclusion and Recommendations**

Based on the key messages and principles of Global Mental Health, existing evidence base and best practices, the author of this article has determined that it is clear that the mental health care system and the mostly institutional-type services in Lithuania could be more effectively reformed and reorganized. As per the main principles of Global Mental Health, it would be important that different Lithuanian Central and Local Authorities start working together with other key stakeholders in an inter-sectoral and multidisciplinary way in order to most effectively achieve the needed change. They would all be invited to first of all acknowledge the gaps in mental health care, treatment and support provision; then, to search

for and promote the more effective and affordable treatments, care and support, as well as to scale up new community-based services. Long-term political commitment would be important here; so, would be the building of respective networks and ensuring of collaboration between all the key stakeholders. As the central aspect, the respect for fundamental human rights of all persons and fostering of the best possible quality of life for individuals, through looking for a better understanding of the origins and causes of mental health problems and psychosocial disability, is emphasized in and invited by the principles of Global Mental Health. Additionally, the reduction of stigma and discrimination against persons who have mental health problems could be addressed as a part of comprehensive systemic change.

In order to generate political will for prioritizing mental health in Lithuania, first of all, a consensus could be reached between mental health and human rights advocates; the objectives and terminology of mental health advocacy could become more clearly defined, making advocacy efforts more focused and informative; and more service users and their families/carers could be empowered to self-advocate. More active advocacy for prioritizing mental health and scaling up of effective services on the principles of scientific evidence and human rights for people who have mental health problems or psychosocial disability are important in the current Lithuanian context. A reallocation of financial and other resources, the development of community-based services, as well as introduction of programs of psychosocial rehabilitation, could all be potentially addressed in parallel with each other. In addition to the above, all of the related planning and decision making could be informed by such key elements as evidence, ethics, and experience; they may also include both community-based and hospital services. Moreover, it is important that the relevant legislation is adequately reviewed: the main piece of legislation currently being the Law on Mental Health Care, which has not been reviewed ever since 1995.

Moreover, the further academic as well as more practical exploration of the possibility to adapt the “task-shifting” model in Lithuania could potentially propose a rational redistribution of tasks and responsibilities among various health teams and providers of medical as well as social services. In order to make more efficient and rational use of the available human resources for mental health, very specific tasks could be appropriately moved, from highly qualified health professionals to community health workers with fewer qualifications, but instead with specialized training and ongoing supervision, as described by Petersen et al. (2011). Additionally, it is important that the decentralization of services and development of secondary care-level, community-based ones becomes a priority on the political agenda, since downsizing the existing mental health institutions would require availability of a wide spectrum of community-based services. The parallel investment in existing care services is also important here, but only if it is in parallel with the development of community-based services. Moreover, there is a significant role for the integration of evaluation and monitoring of the processes, as well as of the new solutions found. Such interventions could focus on using low-cost case management and multidisciplinary approaches, as described by Von Korff and Goldberg (2001). Clear, realistic and measurable indicators could be introduced on the policy and systemic level and attentively, continuously, consistently and independently monitored, evaluated and regularly reviewed from the very beginning of the

deinstitutionalization processes; they could also be complemented with further academic research and expansion of the local evidence base in this field.

In conclusion, whichever more specific path for a more effective systemic reform was to be chosen in Lithuania, the resources for mental health care and support could primarily be decentralized and made more available and accessible in the community; it would be important to include human rights as the central pillar of the newly developed system and services; awareness raising and time would be needed to progress; a mobilization of informal resources in the community could be stepped up; grassroots stakeholders could unitedly advocate for change and take part in the community mental health services development and delivery. Finally, continuous research and evaluation would be important, too, in order to ensure the most effective and human rights based development, improvement of mental health care, treatment, and support services' provision, as well as better health outcomes, as a result of the deinstitutionalization of mental health services in the country.

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