**Response of the Government of Estonia**

**Questionnaire on** **the right of persons with disabilities to the highest attainable standard of health**

1. **Please provide information on existing or planned legislation and policies to ensure the realization of the right to health of persons with disabilities, including current challenges and good practices.**

The **regulatory framework** of the Estonian health system is laid down in five major pieces of legislation: the Health Insurance Act, the Health Services Organization Act, the Public Health Act, the Medicinal Products Act and the Law of Obligations Act.

In 2018, amendments to the **Public Health Act** came into force. The amendments include a new definition of public health which now explicitly stresses the aim and need to reduce health inequalities. The purpose of the Public Health Act is to protect human health, prevent diseases and promote health, which is to be achieved through the performance of duties by the state, local governments, legal persons in public law, legal persons in private law and natural persons, and through the system of national and local measures.

**Requirements for buildings due to the special needs** of persons with disabilities regulation is under development. The general principles for accessibility expressed in the Building Code are based on Article 9 of the United Nations Convention on the Rights of Persons with Disabilities, which provides the right of said persons to accessibility, including access to buildings. The regulation establishes updated and more specific requirements for buildings due to the special needs of persons with disabilities, in order to ensure unobstructed movement and use of the building, including the availability of relevant information.

**National Institute for Health Development** (NIHD) has a role to empower and advise local governments in the field of public health. In 2018, a web-based toolkit is being developed, with the purpose to help local governments analyse the state of their public’s health and plan health promoting activities. One of the aims is to stress the importance of mapping and taking into account the needs of different social groups (including people with disabilities).

1. **Please provide any information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) related to the exercise of the right to health of persons with disabilities in general, as well as with particular focus in the following areas:**

* **Availability of barrier-free general healthcare services and programmes, which take into account all accessibility aspects for persons with disabilities**;
* **access to free or affordable general healthcare services and programmes, including mental health services, services related to HIV/AIDS and universal health coverage**;
* **access to free or affordable disability-specific healthcare services and programmes; and**
* **access to free or affordable health-related habilitation and rehabilitation goods and services, including early identification and intervention**.

The Estonian health system is based on **compulsory, solidarity-based insurance** and almost universal access to health services provided by entities that operate under private law. Stewardship and supervision as well as health policy development are the duties of the Ministry of Social Affairs and its agencies. The financing of health care is mainly organized through the independent Estonian Health Insurance Fund (EHIF).

The main source of health insurance revenues is social health insurance contributions paid by salaried workers and self-employed people. The non-contributing individuals are implicitly subsidized by the other categories, reflecting strong solidarity within the system. Disabled people are in Estonia the non-contributing group, if they are not salaried or self-employed. Non-contributing individuals, including people with disabilities are eligible for the same benefits package as everyone else in the insurance pool. The state contributes additionally to the social health insurance on behalf of a small proportion of the covered population (approximately 3.5% in 2016), including individuals registered as unemployed and caregivers of disabled people.

The **benefits package for all insured population** covers the provision of preventive and curative health services, as well as pharmaceuticals and medical devices, which may be subjected to cost-sharing. Overall, the range of health care benefits covered by the EHIF is very broad. The few services excluded are cosmetic surgery, alternative therapies and optician services. Nevertheless, there are remissions and exceptions for people with disabilities.

For example, there are remissions for out-of-pocket payments for pharmaceuticals. A government regulation lists pharmaceuticals for chronic illnesses that can be reimbursed at a rate of 75% or 100%. A reimbursement rate of 90% is applied to pharmaceuticals in the 75% category when these are prescribed to people receiving disability pensions. Also the annual dental care benefit is higher (85 euro) for disabled people comparing to total adult population (50 euro). EHIF also compensates additionally anaesthesia for patients with disabilities needing dental care. EHIF also compensates for temporary incapacity for work and this includes an allowance which is eligible for people caring for a disabled child under 16 years.

**Access to free HIV-testing**, outpatient health care services provided by infectious disease specialist and antiretroviral treatment is provided to all in need (including persons with disability). HIV-testing and outpatient health care services provided by infectious disease specialist are financed from health insurance fund for persons with health insurance and from the state budget through a contract that covers unavoidable health costs for persons without health insurance. Antiretroviral treatment is financed through state budget for all persons living with HIV and the treatment is free of charge.

By the end of 2017, 5442 people living with HIV were accounted for by the infectious disease specialist and 4109 received antiretroviral treatment.

**Rehabilitation system** in Estonia consists of three main parts – medical rehabilitation, which is provided by the health system and aims to restore impaired functions and preserve the restored functions; social rehabilitation, which is provided by the welfare system and aims to achieve or restore social participation; and vocational rehabilitation, which is provided by the employment system and aims to prepare people with special needs for work, support them in their search for suitable jobs and help them maintain their ability to work. Social and vocational rehabilitation are provided separately from the health system and the need for the services is assessed and decided by the case managers working for the Social Insurance Board or the Unemployment Insurance Fund. These services can be provided after the work ability (in case of people in the working age) or the severity of disability (in case of children and elderly) of the person has been evaluated.

Majority of the hospitals are public entities. Primary care providers are mostly private entities. Nevertheless, **physical conditions and the construction of health facilities**, including general building standards, are regulated for all healthcare service providers (public and private). Standards are specified and all new buildings are required to ensure easy accessibility for all, including people with physical disabilities.

**Surveys and data about disabled persons and health in Estonia:**

* Study of disabled persons (in Estonian language) <https://www.sm.ee/sites/default/files/content-editors/Ministeerium_kontaktid/Uuringu_ja_analuusid/Sotsiaalvaldkond/puuetega_inimeste_uuringu_raport_1_.pdf> (health p 35-36);
* Study of disabled persons and their family members maintenance load (in Estonian language): includes self-perceived health, health problems, activity restrictions, mental health, access to health care (p 35-43) <http://rahvatervis.ut.ee/bitstream/1/4030/1/PIU%202009.pdf>
* Social integration of disabled persons <http://www.rahvatervis.ut.ee/bitstream/1/6196/1/Puudega2014.pdf> (The health status of persons with activity limitations p 172-179).
* Statistics Estonia database where information can be found on:
  + General data of disabled persons <http://pub.stat.ee/px-web.2001/I_Databas/Social_life/05Health/02Disabled_persons/06General_data/06General_data.asp>
  + Contriving of disabled persons: health, accessibility of health care <http://pub.stat.ee/px-web.2001/I_Databas/Social_life/05Health/02Disabled_persons/02Contriving_of_disabled/02Contriving_of_disabled.asp>
  + Employment of disabled persons <http://pub.stat.ee/px-web.2001/I_Databas/Social_life/05Health/02Disabled_persons/04Employment_of_disabled/04Employment_of_disabled.asp>
  + Households with disabled member <http://pub.stat.ee/px-web.2001/I_Databas/Social_life/05Health/02Disabled_persons/08Households_with_disabled/08Households_with_disabled.asp>
  + Time use of disabled persons <http://pub.stat.ee/px-web.2001/I_Databas/Social_life/05Health/02Disabled_persons/10Time_use_of_disabled/10Time_use_of_disabled.asp>
* National Institute for Health Development database where information can be found on:
  + Data in Health Interview survey about limitations in performing usual and daily activities <http://pxweb.tai.ee/PXWeb2015/pxweb/en/05Uuringud/05Uuringud__01ETeU__02Piirang/?tablelist=true&rxid=954f91e4-e6c6-4416-a478-2bcf283a3e73>
  + Data in Survey of Health, Ageing and Retirement in Europe (SHARE) about limitations in performing usual and daily activities http://pxweb.tai.ee/PXWeb2015/pxweb/en/05Uuringud/05Uuringud\_\_08SHARE\_\_02Toimetulek/?tablelist=true&rxid=954f91e4-e6c6-4416-a478-2bcf283a3e73

1. **Please provide information on discrimination against persons with disabilities in the provision of healthcare, health insurance and/or life insurance by public or private service providers.**

As described above, people with disabilities are eligible for insurance coverage without contributing and they are eligible for the same benefits package as everyone else in the insurance pool.

1. **Please provide information on the observance of the right to free and informed consent of persons with disabilities regarding healthcare, including sexual and reproductive health and mental health services.**

According to the **Law of Obligations Act**, which also regulates contract for provision of health care services, the provider of health care services has an obligation to inform the patient of the results of the examination of the patient and the state of his or her health, any possible illnesses and the development thereof, the availability, nature and purpose of the health care services required, the risks and consequences associated with the provision of such health care services and of other available health care services. At the request of the patient, the provider of health care services has to submit the specified information in a format which can be reproduced in writing. A patient may be examined and health care services may be provided to him or her only with his or her consent. A patient may withdraw his or her consent within a reasonable period of time after granting consent. At the request of a provider of health care services, such consent or an application to withdraw such consent has to be in a format which can be reproduced in writing.

In the case of a patient with restricted active legal capacity, the legal representative of the patient has the rights specified above in so far as the patient is unable to consider the pros and cons responsibly. If the decision of the legal representative appears to damage the interests of the patient, the provider of health care services has no right to comply with the decision. The patient has to be informed of the circumstances and information specified in the previous paragraph to a reasonable extent.

The Law of Obligations Act also regulates provision of health care services to patients without capacity to exercise their will. If a patient is unconscious or incapable of exercising his or her will for any other reason and if he or she does not have a legal representative or his or her legal representative cannot be reached, the provision of health care services is permitted without the consent of the patient if this is in the interests of the patient and corresponds to the intentions expressed by him or her earlier or to his or her presumed intentions and if failure to provide health care services promptly would put the life of the patient at risk or significantly damage his or her health. The intentions expressed earlier by a patient or his or her presumed intentions have to, if possible, be ascertained using the help of his or her immediate family. The immediate family of the patient has to be informed of his or her state of health, the provision of health care services and the associated risks if this is possible in the circumstances. The notion of immediate family includes the spouse, parents, children, sisters and brothers of the patient. Other persons who are close to the patient may also be deemed to be immediate family if this can be concluded from the way of life of the patient.

According to the **Termination of Pregnancy and Sterilisation Act**, a woman’s pregnancy may only be terminated at her own request. Nobody is allowed to force or influence a woman to terminate her pregnancy. Consent for termination of pregnancy shall be in written form. Pregnancy of a woman with restricted active legal capacity may be terminated with her own consent or with the consent of her legal representative according to the Law of Obligations Act. If a woman with restricted active legal capacity does not agree to involve her legal representative with good reason in the case provided for in the Law of Obligations Act or if the decision of the legal representative is in conflict with the interests of the woman, the health care provided has to proceed from the person’s own consent upon termination of pregnancy. A health care professional is required to inform a woman with restricted active legal capacity of the importance to involve a legal representative or another adult with active legal capacity whom she trusts.

The Termination of Pregnancy and Sterilisation Act specifies also cases the pregnancy which has lasted for more than 12 and less than 22 weeks may still be terminated. Among those is when the illness or health problem of a pregnant woman hinders the raising of a child. The admissibility of termination of pregnancy in this case has to be ascertained with the decision of at least three doctors – two or more gynaecologists and a medical specialist or specialists resulting from the woman’s illness or health problems. If necessary, also a social worker has to be involved in the making of a decision in addition to doctors.

Before the termination of pregnancy, the health care professional must explain to the woman who wishes to terminate her pregnancy or in the case of a patient with restricted active legal capacity to the legal representative the biological and medical nature of termination of pregnancy and the involved risks, including the potential complications. An act has to be prepared on this obligatory counselling, signed by both the counselled person and the health care professional having conducted the counselling.

If necessary, the health care professional informs a pregnant woman or a woman who wishes to terminate her pregnancy or in the case of a patient with restricted active legal capacity her legal representative of the psychological and other relevant counselling possibilities, if necessary.

According to the Termination of Pregnancy and Sterilisation Act, a person may only be sterilised at his or her own request (in written form). The sterilisation of a person with restricted active legal capacity has be decided by a county court in proceedings on petition of the guardian of a person. Minors may not be sterilised.

An adult with restricted active legal capacity may be sterilised if at least one of the following conditions exists: 1) pregnancy endangers the woman’s health; 2) other contraceptive devices are contraindicated; 3) the person is in danger of having a child with severe mental or physical damage to health; 4) the person’s illness or health problem hinders the raising of a child. The admissibility of sterilisation in the first three of these cases has to be decided with the decision of at least three doctors. If necessary, a social worker also has to be involved in the making of decision in addition to the doctors in the fourth case.

Before and after deciding on the admissibility of sterilisation, the doctor must explain to the person who wishes to be sterilised and, if necessary, to the guardian of the person the biological and medical nature of sterilisation and the involved risks, including the potential complications. An act has to be prepared on the counselling which shall be signed by the counselled person and the doctor having conducted the counselling. A person cannot be sterilised before one month has passed since the counselling.

According to the **Mental Health Act**, psychiatric care is provided on a voluntary basis, i.e. at the request or with the informed consent of a person. Psychiatric care is provided to a person with restricted active legal capacity with the consent of his or her legal representative and on the basis of the person’s will insofar as the person is able to express his or her respective will. A legal representative cannot express his or he will for the provision of psychiatric care instead of the principal.

The treatment of a person with a mental disorder without his or her informed consent is permitted only in the cases provided for in §§ 11 and 17 of the Act (the translation of the Mental Health Act can be found at: <https://www.riigiteataja.ee/en/eli/501022016017/consolide>). The same applies to the provision of psychiatric care to a person with restricted active legal capacity and his or her treatment if the person is unable to express his or her will or if the guardian does not consent to the care or treatment.

1. **Please describe to what extent and how are persons with disabilities and their representative organizations involved in the design, planning, implementation and evaluation of health policies, programmes and services.**

Patient involvement in health care has become more significant in recent years in Estonia. For example, the Estonian Chamber of Disabled People, an umbrella organization, including for condition-specific societies, is represented on the Estonian Health Insurance Fund Supervisory Board.

The Estonian Chamber of Disabled People is also involved in other healthcare related working groups. For example, they are represented in the Guideline Advisory Board, which was established in 2011 to improve the quality of health services by supervising the development of efficient and evidence-based clinical guidelines.

Estonia also has many patient groups representing people with specific illnesses or disability, such as the Diabetic Society and the Multiple Sclerosis Society. The patient representatives are involved in the discussions regarding important healthcare policy changes.