**To Special Rapporteur on the rights of persons with disabilities**

**Dear Ms. Catalina Devandas-Aguilar,**

I have reviewed your appeal regarding the right of persons with disabilities for health care and would like to inform you on the following.

I note with regret that due to Russian aggression and military operations in the East of Ukraine there is a tendency of increasing of the number of persons with disabilities. As of 2017, according to the information provided by the Ministry of Social Policy of Ukraine, there are more than 2.6 million persons with disabilities in Ukraine (without taking into account the data on Crimea and Sevastopol).

There is a number of laws which regulate protection of rights of persons with disabilities in the healthcare field (in particular, the Law of Ukraine "On the Fundamentals of Social Protection of Persons with Disabilities in Ukraine" No. 875-XII of 21 March 1991, "Fundamentals of the Ukrainian Legislation on Health Care" No. 2801-XII of 19 November 1992, "On Rehabilitation of Persons with Disabilities in Ukraine" No. 2961-IV of 6 October 2005, "On State Social Aid for Persons with Disabilities from Childhood and Children with Disabilities" No. 2109-III of 16 November 2000, "On Psychiatric Aid" No. 1489-III of 22 February 2000, "On Protection of Childhood" No. 2402-III of 26 April 2001) and other bylaws.

After ratifying the Convention on the Rights of Persons with Disabilities on 16 December 2009, Ukraine has undertook respective obligations in the sphere of ​​protection of rights of this category of citizens, including the right to health care.

The main tasks and measures for the fulfillment of rights of persons with disabilities to health care are enshrined in the State Target Program "National Action Plan for the Implementation of the Convention on the Rights of Persons with Disabilities" for the period up to 2020, approved by the resolution of the Cabinet of Ministers of Ukraine No. 706 of 01.08.2012. Also, appropriate measures are envisaged by the Action Plan for the implementation of the National Strategy on Human Rights for the period up to 2020, approved by the Resolution of the Cabinet of Ministers of Ukraine of 23 November 2015 No. 1393-r.

In order to impose the measures envisaged by the mentioned legal acts, the reform of the health care system is being implemented.

Thus, in 2017 the Parliament adopted the Law of Ukraine "On State Financial Guarantees for Medical Care of the Population", which defined the state financial guarantees for the provision of medical services and proper quality medicine at the expenses of the state budget under the program of medical warranties.

At the same time, the implementation of the said Law should take place with a simultaneous application of the mechanism of compulsory state health insurance. The respective draft laws, submitted by the subjects of the legislative initiative to Ukrainian Parliament, are currently under consideration in its specialized committee.

It should also be noted that the Ministry of Health of Ukraine, together with other executive bodies and the civil society, is working on the implementation of the International Classification of Functioning, Disability and Health (ICF) in Ukraine. One of the first steps was the approval by the resolution of the Cabinet of Ministers of Ukraine of 27.12.2017 № 1008-r of the Plan of measures for the implementation of the International Classification of Functioning, Disability and Health and the International Classification of Functioning, Disability and Health for Children and Youth in Ukraine. According to this Resolution, during the 2018-2019 period, the central executive bodies shall take appropriate measures to implement the ICF.

Thus, there is a transition from the existing medical and social models of disability to the biopsychosocial one, which will allow a person with disability, taking into account the state of his/her health, to adapt to the maximum extent to the social environment.

The Commissioner for Human Rights constantly monitors the resolution of the main problematic issues related to the enjoyment by persons with disabilities of their rights, including the right to health care. The respective problems and proposals for their solution are highlighted in the annual and special reports of the Commissioner drafted in accordance with Article 18 of the Law of Ukraine "On the Ukrainian Parliament Commissioner for Human Rights". The shade report on implementation of the UN Convention on the Rights of Persons with Disabilities, which was sent to the UN Committee on the Rights of Persons with Disabilities, and which was reviewed at the 14th session of the Committee in Geneva in August 2015, as well as the annual report of the Commissioner for Human Rights on the protection of the rights and freedoms of a human and a citizen in Ukraine, 2017 can be accessed on the website of the Commissioner for Human Rights (www.ombudsman.gov.ua).

It was established that general problems of the health care system are mainly caused by insufficient funding of the sector. This negatively affects the most vulnerable category of population – persons with disabilities. In particular, this concerns insufficient funding of state or local programs for the provision of certain categories of persons with disabilities with medicine, medical products, medical services, as well as certain physical inaccessibility of health care facilities for persons with disabilities and the absence of the concept of universal design and reasonable accommodation in these institutions.

In addition, attention should be paid to the incomplete process of the creation of the Centralized Database on Disability as a unified system for collecting and aggregating statistical data on the number of persons with disabilities and their needs. As a result, it is impossible to provide an objective assessment of the needs of persons with disabilities.

At the same time, the legislation of Ukraine guarantees persons with disabilities access to free or low-budget medical and rehabilitation services and programs.

In particular, according to the Resolution of the Cabinet of Ministers of Ukraine of 17August 1998, No. 1303 "On the ordering of free and preferential provision of medicines by doctor’s prescriptions in case of ambulatory medical care of certain categories of population and for certain diseases", persons with a disabilities have the right to receive medicines registered in Ukraine and which are part of the sectorial standards in the healthcare field gratuitously or on preferential terms.

The mentioned Resolution of the Cabinet of Ministers of Ukraine stipulates the list of social groups and illness categories when the medicines are available on prescription gratuitously or at preferential prices in a case of ambulant therapy.

Thus, medicines are available on prescription gratuitously or at preferential prices for patients with schizophrenia and epilepsy; mental health disorders (disabled persons of the first and the second group, as well as patients engaged at work therapy workshops at the psycho-neurological institutions and mental health facilities); people living with HIV/AIDS.

Meanwhile, according to the monitoring of the situation by the Commissioner for Human Rights guaranteed by the legislation preferential terms for medicines are not fully implemented due to inadequate funding.

Whereas an ample quantity of vitally necessary medicines were not included in the National essential medicines list approved by the Resolution of the Cabinet of Ministers of Ukraine No. 180 of 16 March 2017 that has contributed to the problems of providing people with medicines on preferential terms in 2017.

Relevant observations and proposals of the Commissioner directed towards Prime Minister of Ukraine for tackling the problem were taken into account. As a consequence, the National essential medicines list has been widened with 60 international generic names of medicines (resolution of the Cabinet of Ministers of Ukraine No. 1081 of 13 December 2017).

 In 2016-2017 Commissioner has received a significant number of complaints on inadequate ensuring the rights of people with a disabilities affected by rare (orphan) diseases in the public health sector.

As a part of ongoing proceedings it was established that failure of the state authorities to take proper and effective measures to adequately finance the regular and free-of-charge provision of orphan patients with medicines and appropriate foods for special dietary consumption, their treatment has been interrupted and the life expectancy of such patients has been lessened considerably.

Through the joint efforts of NGOs and the Secretariat of the Commissioner with the participation of the Ministry of Health of Ukraine the «orphan disease» has been defined, list of «orphan diseases» (comprises 275 afflictions) has been modernized and brought into line with European norms, lifetime supply of medication for people affected by orphan diseases has been required, the Centre for Orphan Disease based at the Okhmatdit Ukrainian Specialized Children's Hospital has been established and cooperates with the similar centers in other countries according to adopted laws and regulations.

Despite some progress in improving legislation there is a number of issues are still remained unresolved. In particular, the register of orphan patients has not been established; there have been difficulties in providing treatment for such patients among adults; public procurement is not carried out in time; the individual requirements of patients have not been taken into account in the procurement process.

According to the resolution of the Cabinet of Ministers of Ukraine No. 1301 of 03 January 2009 «On Amendments to the Regulation on supply persons with disabilities and children with disabilities with assistive and other rehabilitation devices» such people are provided with assistive and other rehabilitation devices (e.g. hearing aids, urine-collecting bags, ostomy pouching systems, valve prosthesis, set for the percutaneous coronary angioplasty (PTCA) with stents without therapeutic coverage, cochlear implants, joint and heart implants etc.)

Provision of such devices shall be provided on the basis of a medical certificate and financed within State and Local Funds.

In 2017, Commissioner received a number of appeals from ostomy patients regarding the provision of relevant devices.

As it was established within the proceeding there were a lot of regions where the register of ostomy patients are not appropriately maintained. Meanwhile, the registered patients are supplied partially (in view of lack of adequately funding) as a result they are forced to buy with their own money.

There is a fruitful cooperation between the Commissioner and NGO «All-Ukrainian organization of disabled persons «Ostomiia» in tackling this issue. In the light of the discussions on ostomy patients’ challenges highlighted on the workshops and roundtable meetings organized by mentioned NGO, relevant applications to various levels of government have been drafted, as well as measures have been taken to ensure adequately funding of current regional programs to protect the rights of mentioned category of persons with disabilities.

Problems of ostomy patients were discussed during the session of the Council for Persons with Disabilities of the Cabinet of Ministers of Ukraine on 28 November 2017. As a result, in January 2018 working group based at the Ministry of Health of Ukraine was established by the Council to work on [certain tasks](http://context.reverso.net/%D0%BF%D0%B5%D1%80%D0%B5%D0%B2%D0%BE%D0%B4/%D0%B0%D0%BD%D0%B3%D0%BB%D0%B8%D0%B9%D1%81%D0%BA%D0%B8%D0%B9-%D1%80%D1%83%D1%81%D1%81%D0%BA%D0%B8%D0%B9/certain%2Btasks). In particular creation of the register (data base) of persons with disabilities who require medical devices (urine-collecting bags, ostomy pouching systems), adopting the minimum standards for the providing persons with disabilities with medical products financed from the budget, and ensuring an individual approach when supplying the persons with disabilities.

The Representative of the Secretariat of the Commissioner for Human Rights is included to the working group.

Within the individual rehabilitation program persons with disabilities are also provided with technical and other devices for the rehabilitation through the structural units of the local public administrations for social protection of population under the Resolution of the Cabinet of Ministers of Ukraine No. 321 of 05 April 2012 «On Approval of the Regulation on supply persons with disabilities, children with disabilities and other specific categories of population with assistive and other rehabilitation devices, a list of such devices». The mentioned list stipulates that persons with disabilities may be provided with, in particular, prosthetic-orthopaedic products; special equipment for self-service and care; equipment for transportation; equipment for personal mobility, moving and lifting; furniture; special devises for orientation, communication and exchanging of information, etc.

However, the results of the monitoring, conducted by the Commissioner for Human Rights on this issue, has shown that the funds allocated in 2017 to the departments for social protection of the population were insufficient to cover the actual needs of technical and other facilities of rehabilitation.

Situation with rehabilitation of people with intellectual and psychosocial disorders remains difficult.

According to the new Standard Statute on the Psychoneurological Residential Care Facilities approved by the resolution of the Cabinet of Ministers of Ukraine No.957 of 14 January 2016, persons who reside in institutions of boarding type have the opportunity to receive a complex of rehabilitation services in accordance with an individual rehabilitation program. For the first time the Statute provides for the establishment of various departments (intensive and palliative care, supported accommodation, etc.), taking into account the individual needs of the wards. The approval of the Implementation Plan of the pilot project "Establishment of a system rendering early intervention services" 2017-2020 has become an important step ensuring child development, preserving its state of health and life.

The main idea is to provide appropriate services based on existing model in the institutions of Lviv, Kharkiv, Transcarpathia and Odessa regions. Project implementation shall be resulted in designing and approval of the general principles and standards for the provision of early intervention services; rules of interaction between the institutions providing such services; Statute for the operation of the center (branch, office) providing early intervention services, templates of the documents; the procedure for early detection (screening) of child’s lagging and developmental disorders; staff specifications and qualification requirements for specialists providing these services; costs and sources of funding, etc.

The effectiveness of the implementation of this project can be assessed after studying the information provided by the Ministry of Health Care of Ukraine on the status of its implementation, in particular, on the results of the previous year. Participation of civil society organizations of persons with disabilities is of a key importance to forming the state policy in the sphere of protection of the right of persons with disabilities to health care.

In particular, the adoption of normative legal acts on the issues related to the rights of persons with disabilities is always preceded by consultations with the publics, organized and held by the main drafter of the respective legal act. The information about these consultations is published in the specifically created section "Public consultations" on the official web site of the executive body. At the request, representatives of all-Ukrainian public organizations of persons with disabilities and its unions may become members of boards and advisory bodies of the central executive authorities.

The representatives of local public organizations of persons with disabilities and its unions may become members of the boards and advisory bodies at the local level. For example, the representatives of 35 NGOs, including those organizations, which unite persons with disabilities, are included in the Public Council of the Ministry of Health of Ukraine.

All-Ukrainian "National Assembly of the Disabled of Ukraine" (NADU) has been functioning in Ukraine since 2001. Its activities are aimed at improving the situation of persons with disabilities in Ukraine, promoting their constitutional rights, enhancing their role and social status in society.

The Office of the Commissioner for Human Rights also cooperates with various NGOs in solving problematic issues of ensuring constitutional rights and state guarantees for persons with disabilities in the sphere of health care (examples of such cooperation were previously mentioned).

Looking forward to our further cooperation and, considering my respective mandate, I would like to express readiness to provide any other additional information concerning promotion and protection of human rights and freedoms in Ukraine, including rights of persons with disabilities.

**Liudmyla Denisova**