OPEN LETTER TO THE GOVERNMENT

In these days we are reading worrying news coming from overseas and from European Union member countries: the provisions given by hospital administrations to doctors regarding the so-called "triage" - also due to the lack of electro medical devices - would provide for a selection of patients to be subjected to intensive care, in which the presence of disabilities and in particular of the cognitive one, would represent a barrier to adequate care, based on heterogeneous motivations.

It is clear that this news provokes the indignation of all people with a civic sense, as each country that considers itself "civilized and respectful" recognizes the duty to ensure equal quality of care for all, based on moral criteria and not based on arbitrariness.

As associations that promote and protect human, civil and social rights and the quality of life of people with disabilities and chronic, oncological, rare and complex diseases, we ask that preventive actions be implemented so that we do not find ourselves in front of the need to choose which human lives deserve to be saved and which ones you sacrifice.

To this end, we appeal to what is the subject of the opinion of the bioethical committee of the Republic of San Marino, which unequivocally sanctions as otherwise, even if reference was made to the criteria indicated in the cases of the so-called "Medicine of Disasters", to be harmed would be the fundamental rights of the individual and, therefore, how such distinctions cannot be practiced or practicable by virtue of any reason, even if of a "medical" nature.

Indeed, we deem that it is urgent and necessary to implement, as it has already been done, the possibility of preparing emergency beds, taking into account in this implementation the specific needs of people with serious and/or chronic, rare and complex diseases and greater attention due to those people who are unable to understand the instructions they are provided or do not collaborate because of their condition of disability or illness, creating special dedicated wards / structures where possible, especially for the implementation of life-saving therapies that many must continue to do and that some are suspending, for fear of contagion, putting their health and life at risk.

Furthermore, we specify that it is of fundamental importance to act even more effectively "ab origine" and for precautionary purposes, giving concrete follow-up to the Protocol for the prevention and safety of Healthcare, Social Health and Social Care Services workers in relation to the health emergency from «Covid-19» stipulated on March 24 as an addendum, distributing Personal Protective Equipment wherever necessary, and to the Ministry of Health Circular dated March 25, 2020, where we would like to point out that a specific reference to the people living with Rare Disease would be appropriate among the fragile conditions.

Rome March 31, 2020
In conclusion, we ask that all appropriate tools be put in place to ensure that people with disabilities or with chronic, rare and complex diseases are better protected, both by implementing preventive measures of the risk of infection, and, where the infection has already occurred, preventing that their health condition worsens to the point of requiring hospitalization. Clearly, at this time, any access to the hospital, even for life-saving therapies, is an additional source of risk and anguish for themselves and their families, as well as for the burden of the work of health personnel already prostrated by the CoVid-19 emergency.

It remains understood that, if hospitalization becomes necessary, access to equal quality care must be guaranteed to all patients, without any discrimination based on pre-existing health conditions, nor of age or disability of the person.

For the sake of clarity, we summarize our requests below:

- that there is no discrimination in access to intensive care because of one's health or disability condition or for any other reason based on arbitrariness;
- that access to home therapies is enhanced wherever possible, avoiding avoidable admissions to hospitals; where it is not possible that safe pathways are guaranteed, far from possible sources of infection;
- that adequate support is provided to family members and people with disabilities in case of need for hospitalization. This support must be guaranteed from the moment of pick up at home of the patient with the ambulance and ensured in all subsequent phases, especially if in intensive care. To this end, a specific person of reference should be identified, with psychological skills, which can support the family and act as link with the disabled person hospitalized (who could be disoriented with respect to the situation) in order to reduce the stress, and also acting as facilitator in understanding the dynamics related to the environment and decoding, especially in the case of serious non-verbal disability, the needs and communication of symptoms.
- that contact persons are identified and adequately trained to support the hospitalization of people with intellectual and neurodevelopmental disabilities and / or with chronic, rare and complex diseases, for each hospital unit, available in all cases of need and with the possibility full time coverage;
- that, similarly to what has been done for the reporting of health emergencies, a Social and Socio-health Emergency Service is established at the socio-health district level; also establishing telephone lines that collect the requests of citizens with intellectual and neuro developmental disabilities or with chronic, oncological, rare and complex diseases or, again, not self-sufficient, who need specialist medical services in urgency and safety and therefore a reference point that can give an answer in definite time.
- that a concrete response is also offered to situations of social emergency, with particular attention to people with disabilities who are not collaborating and / or are not self-sufficient, as they are unable to perform the essential acts of daily life without the assistance of a caregiver. We point out that these people often have poor protection of the
family network as they tend to live alone in the house with the family assistant and / or with elderly or disabled family members. In addition, they may also not have family members, among those indicated in art. 433 of the Italian Civil Code, who live at a reasonably reachable distance or in the same municipality (also in light of the restrictions imposed by recent measures to contain the spread of the infection);

● That home care is reactivated guaranteeing safety conditions for social workers who provide it, beneficiaries and their families, and this both for those who already were benefiting it and for those who previously used services in structures/day centres whose activities have been suspended. This is in order to guarantee our people and their families the support they need most in this difficult moment;

● furthermore to better deal with these critical issues, we deem necessary the availability of a continuous remote assistance service to monitor the situation and intervene where necessary, for example by using social workers.

In support of our requests, we are ready to contribute also with fundraising campaigns, already active in many parts of Italy by many associations, aimed at the purchase of ventilators and other materials to be delivered to hospitals in need, and with the help of our volunteers.

Up-date over 200 Umbrella Organisations and POs have signed the open letter.

Go to http://www.uniamo.org/lettera-aperta-al-governo-2/ to sign it