

SARS-COVID-19 Pandemic and Persons with Disabilities in Italy and Europe

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1. General situation

The spread of COVID-19, as the WHO General Director Tedros Adhanom Ghebreyesus said, has now reached the level of pandemic – defined as “an epidemic occurring over a very wide area, crossing international boundaries and usually affecting a large number of people”³ - as the most disturbing epidemic since the Second World War. Currently, the WHO reports over 88,828,387 persons infected and more than 1,926,625 deaths, with Europe recording 28,794,000 infections with 626,726 deaths (updated January 1st, 2021)⁴. Government interventions, which are getting progressively more drastic but necessary, have upset and curtailed the most common lifestyle habits such as having a coffee at a café or bar, having a friendly chat with the barber, going shopping, or going out with friends. In all this, where people have their freedom restricted, what is happening to persons with disabilities?

2. Persons with disabilities and humanitarian emergencies

The issue of persons with disabilities, in emergency and humanitarian interventions, has only recently entered international debates. It was prompted by the case of the refugee camps in Kosovo during the war in former Yugoslavia, re-proposed (in dramatic terms) with the tsunami in Indonesia (where the treatment of persons with disabilities often violated human rights). Also, in Haiti, during the 2010 earthquake, as many as 4,000 people were amputated, only because there weren't enough health units, and so those people did not have adequate support, not only in the provisions of prosthesis and orthoses, but also

with regard to adequate and proper psycho-social support for them to rebuild their lives, after these sudden and drastic changes⁵.

The debate on the subject of rights for persons with disabilities received the approval of the *Convention on the Rights of Persons with Disabilities (CRPD, 2006)*⁶, and many resolutions guaranteeing that all persons with all types of disabilities must be afforded all human rights and fundamental freedoms, were adopted. It was ratified by 182 countries (94.6% of the member countries of the United Nations) and has now become an international standard to be respected, not only in legal terms but also in cultural and technical terms.

Indeed, *CRPD*, which is based on a rights-centered approach, highlights the suffering of persons with disabilities in a society that has created barriers and obstacles (by social exclusions, discrimination and lack of equal opportunities) to inhibit their self-development and involvement in life/work activities, as they are too often victims of human rights violations.

The convention highlights that “*disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others*” (Preamble, letter *e*): this definition revolutionizes the traditional vision, based on a medical model of disability, assigning responsibility for a condition of disability to states and society, through a social model of disability based on respect for human rights. The set of organizations and services of society creates barriers, obstacles, and discrimination, and it is the responsibility of society itself and of states to reduce the causes of disability.

This enhanced sense of responsibility is all the more applicable in the field of humanitarian and emergency interventions. In fact, article 11 (*Situations of risk and humanitarian emergencies*) states: “States Parties⁷ shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters”. The CRPD approach therefore recognizes the following: persons with disabilities must enjoy all human rights in conditions of equality with other citizens; the condition of persons with specific characteristics depends on evolving bio-psycho-social factors that can be modified in the social and individual spheres; the removal or reduction of the causes of disability is a responsibility of states and society; the condition of disability is reduced or removed by attending to health, social, and human factors; the condition of disability, being a part of life everywhere, concerns all policies and requires giving matters of disability adequate attention, benefiting the whole of society. These elements, applied to emergency conditions, require reformulation of policies as well as technical and professional interventions in the field of humanitarian aid.

The international debate in recent years has deepened concerning specifically the theme of the protection and safety of persons with disabilities, by guaranteeing this group equal opportunities and nondiscrimination. The *Verona Charter (2007)*⁸ began to define the general principles underlying emergency interventions for persons with disabilities by producing an internationally oriented series of articles and manuals, exploring the themes elaborated above, relating to non-governmental organizations and organizations of persons with disabilities⁹. In 2015, the Italian Development Cooperation published a *Vademecum on Humanitarian Aid and Disability*¹⁰, the first handbook of its kind composed on the subject by a government.

The United Nations has also issued a series of documents on the subject of humanitarian aid and emergency interventions: the *Sendai Framework for Disaster Risk Reduction (2015)*¹¹

and the *Charter of Istanbul for Inclusion of Persons with Disabilities in Humanitarian Action (2016)*¹². According to the latter, in July 2019, an IASC¹³ task team completed the *Guidelines for Inclusion of Persons with Disabilities in Humanitarian Activities*¹⁴, after two years of work, involving leading experts in the field.

The element that connects all these documents is to ensure that humanitarian and emergency aid is respectful of everyone’s human rights. In fact, the humanitarian approach was based on methods of rapid intervention similar to those of military bodies or charitable organizations (Army, Red Cross, etc.) prevailed. This humanitarian approach, based on limiting losses¹⁵, worked well with the culture of the charitable approach, based on the idea that the beneficiaries of the interventions are incapacitated and need only assistance. However, the Triage approach¹⁶ (involving a discrete selection of which people should be assisted first, second, and so forth) penalizes persons with disabilities.

The humanitarian approach is based on a two-stage intervention. In the first intervention, the essential elements for the rescue and the first reception (food, health and a place of hospitalization) must be guaranteed; afterward, any “special” needs are put in place. The label “special”¹⁷ almost always translates to a separate, second-place, and invisible category.

Preventive and operational practices to reduce the risks deriving from disasters must be based on multi-risk and multi-sectoral approaches that are inclusive and accessible in terms of efficiency and effectiveness¹⁸. In the spirit of resilience, governments should work with communities, particularly with women, children and young people, persons with disabilities, the elderly, and volunteers in designing policies, plans and standards. Along with this spirit of resilience, governments and communities need to anticipate problems that may arise, by activating all human, community, and institutional resources in an organized and effective way to prevent risks and protect the entire population.

Further, all strata of society must be activated and energized, with participation based on empowerment and inclusion, on accessibility and non-discrimination, paying special attention to those affected disproportionately by disasters,

especially the poorest and discriminated sections of the population. Gender, age, disability, and local cultures must be considered in all policies and practices, where strong participation of women and young people is promoted, and voluntary citizenship associations are involved and strengthened.

The European Union and the Council of Europe also responded to the issue of the inclusive emergency of persons with disabilities. The Council of Europe, after a series of consultations with the sector players, in 2016, defined a specific manual as a contribution from the EUR-OPA program¹⁹.

The European Union has approved several documents and policies on the issue of humanitarian aid and emergency, such as the *European Consensus on Humanitarian Aid* (2007)²⁰, concerning attention to persons with disabilities in international cooperation; the *Conclusions of the European Council “on disability-inclusive disaster management”* (2015)²¹, providing specific attention to the inclusion of persons with disabilities in emergency interventions; the operational guide, *The Inclusion of Persons with Disabilities in EU-funded Humanitarian Aid Operations* (2019)²², involving organizations of persons with disabilities in emergency activities, reconciling their knowledge and resources useful for emergency. Further, the European Union has implemented a *European Disability Strategy* (2010-2020)²³ dealing with humanitarian and emergency aid activities, while taking into account the rights and needs of persons with disabilities.

Unfortunately, what emerged in the COVID-19 pandemic is the almost complete absence of persons with disabilities in the emergency interventions implemented in the various European countries.

The lack of coordination between welfare systems²⁴ and emergency intervention systems has made it difficult to identify persons with disabilities, resulting in only partial intervention, too often only purely or partially compensatory.

3. The protection of the human rights of persons with disabilities during the COVID-19 pandemic in Italy

The new emergency response to the COVID-19 pandemic has led to some negative consequences for persons with disabilities. In fact, in many areas of intervention and solutions, the difficulty emerged in protecting and guaranteeing equality of opportunity and non-discrimination for persons with disabilities. We will analyze the Italian case, one of the countries most affected by COVID-19 (2,276,491 infected and 78,755 dead) (January 1st, 2021)²⁵.

After fifteen days from the government declaration of the presence of a COVID-19 epidemic, the Italian Society of Anesthesia, Analgesia, Intensive Care and Intensive Care (SIAARTI) launched recommendations on how to intervene in a pandemic emergency situation in the presence of limited instrumental and logistical resources²⁶, given the sudden surge of COVID-19 patients. These recommendations started a debate among doctors, in particular, among anesthesiologists and heads of intensive care units. If the resources of beds and machinery are limited, if physicians had to choose whom to assist first, who should be “discarded”, using triage, as a “throwaway”, a term similar to one used by Pope Francis, to refer to disenfranchised people²⁷? Young persons or elderly persons? “Normal” persons or persons with severe functional limitations?

Given shortages in medical staff, material resources, and logistical support, SIAARTI recommended the probability of survival, life expectancy, severe comorbidities, functional status, with a view to “*maximizing the benefits for the greatest number of persons.*” However, the practical results of the SIAARTI recommendations meant that the elderly (probability of survival, life expectancy) and persons with disabilities (severe comorbidities, functional status, disability) were effectively excluded from treatment.

In the Republic of San Marino, the National Bioethics Committee (CSB), which has given much attention to the issues of disability by including provisions in all the documents it

approves, at the request of the Extraordinary Commissioner for SARS-COV-19 emergency in the Republic of San Marino (a request that took into account the SIAARTI Recommendations), on March 16th, 2020 approved unanimously a document (*Opinion on use of invasive assisted ventilation on patients with disabilities*²⁸) in which he clarified that only the clinical situation must be used to evaluate a patient's condition and access to care. In fact, citing the *Universal Declaration on Bioethics and Human Rights*²⁹ and *CRPD*, the CSB Opinion recalled that the basic principles to be applied are those of non-discrimination and equal opportunities. It therefore reported that *CRPD* dedicates a specific article (art. 11) to "*risk situations and humanitarian emergencies*" which obliges State Parties to adopt "*in accordance with the obligations deriving from international law, including international humanitarian law and international human rights standards, all necessary measures to ensure the protection and safety of persons with disabilities in risk situations, including situations of armed conflict, humanitarian emergencies and natural disasters*", requiring "*health specialists to provide persons with disabilities care of the same quality as those provided to others*" (art. 25). Any other approach would violate the principles of bioethics and respect for human rights.

The debate immediately moved to an international level, both for the attention of international organizations of persons with disabilities and for the widespread dissemination of the CSB opinion. At the start of the COVID-19 pandemic, the *European Disability Forum*, an organization representing about 90 million citizens with disabilities within the European Union³⁰, immediately defined a series of initiatives, requesting the positions of the European authorities, organizing international webinars, coordinating with other international organizations to promote respect for the human rights of persons with disabilities³¹. Within a few days, one after the other, the most important international organizations came forward, including UNESCO³², the European Group on Ethics in Science and New Technologies³³, DH-BIO³⁴ and many national bioethics committees³⁵. All these institutional responses reiterate that the only approach in a medical triage is the clinical

one and any category-based approach (the elderly, persons with disabilities) would constitute a violation of human rights, on which respect Bioethics is based on.

Unfortunately, the discriminatory approach has been practiced in some European Countries³⁶ and in some states of the US³⁷ (*CRPD has not been ratified by the US*).

The SIAARTI recommendations relating to persons of disabilities have indeed influenced similar responses in other European countries as well as other parts of the world, and the recommendations have realized some, but not all views of the *CRPD* relating to how disaster medicine is practiced.

Indeed, in Italy, a heated discussion has opened on the recommendations of SIAARTI, raised by the National Federation of Orders of Surgeons and Dentists, who have accused SIAARTI of violating professional codes of ethics³⁸.

4. The theme of the protection of the elderly and persons with disabilities

The pandemic in Italy reached extremely high peaks in March and early April 2020³⁹. The number of infected patients, the use of intensive care, and the number of deaths reached dramatic peaks, echoed later in other European countries, highlighting the Italian healthcare system's lack of preparedness in coping with the Covid-19 emergency. In the second half of March 2020, an unimaginable phenomenon was highlighted: in the long-term care residences for elderly people and persons with disabilities, initially in Lombardy, then in various regions of Italy, the epidemic struck a terrible number of patients. The *Italian College of Health*, urged by the *National Guarantor of the Rights of Persons Detained or Deprived of Personal Liberty*, launched a sample survey on assisted healthcare residences (RSA⁴⁰ for elderly non-autonomous person) which highlighted a high level of inpatient death⁴¹. On May 5th, 2020, the Italian College of Health published a final report showing that out of 3,292 institutions surveyed (96% of the total), in the online map of dementia services created by the ISS Dementia Observatory (residential, public and / or affiliated health and social contract

facilities, which welcome persons mainly with dementia) had answered the questionnaire. In 1,356 of these institutions (41% of the total), there were 3,772 deaths from COVID-19 and similar symptoms (41.2% of patients in care). The total is most likely attributable almost entirely to the COVID-19 virus because the autopsies and swabs were not done to the hospitalized. Of the 5,292 persons hospitalized in the period under review, 2,986 were suspected of COVID-19 and with similar symptoms, equal to 56.4% of the total. The analysis of the time intervals of deaths shows that at the beginning of the emergency, no protective provisions had been put in place and that the death trend only drops from 1 to 15 April 2020, while the mortality remained at 16%. In fact, considering the incubation periods of COVID-19, calculated at 6 to 14 days⁴², the lack of the protective provisions in the long-term care facilities during the first period of the pandemic results is clear. Combining the relevant data (lack of personal protective equipment for 77.2% of the institutions, difficulty in accessing swabs for 52.1%, absence of personnel for 33.8%, lack of specific training, difficulty in activating rooms for patients in quarantine, lack of physical distancing between patients and operators, lack of symptom monitoring systems, etc.) and the average number of people hospitalized in the institutions surveyed (74 beds, with a spectrum ranging from 6 to 667 places) those organizations designed to protect people have not protected these most vulnerable people, in case of contagion; on the contrary, the organizations have canceled the most vulnerable persons from the protection systems. If we think that in some regions, particularly Lombardy, elderly persons with COVID-19 symptoms were hospitalized in RSAs, it is evident that these practices have also highlighted violations of Article 15 of the CRPD⁴³. After September 2020, in Italy, the high number of deaths in homes for the elderly with disabilities continues⁴⁴ and many families of assisted persons in residences filed criminal charges for lack of protection of their loved ones⁴⁵.

The *National Guarantor of the Rights of Persons Detained or Deprived of Personal Liberty*⁴⁶ also showed concern about forbidding patient visits to the facilities. According to the National Guarantor, “*the access of relatives*

and visitors to hospitals and assisted healthcare residences (RSA), hospices, rehab facilities and residential care facilities for the elderly and self-sufficient is limited to only the cases indicated by the health management of the institution which is required to take the necessary measures and prevent possible transmissions of infection (...) while considering the appropriate restrictions in order to prevent the spread of the pandemic, he expresses his concern about the repercussions that these limitations can have within the institutions for persons with disabilities and the elderly, if not properly monitored and controlled. In fact, the situation exposes both guests and operators to high stress. This entails an increased risk of conflicting behavior, of mistreatment or of abuse of restraint tools.” Only at the end of April, the Italian College of Health decided to extend the research to long-term residential facilities for persons with disabilities, after various articles⁴⁷ in newspapers showed similar restrictions on patient visits.

The pandemic has brought out various problems which have severely affected persons with disabilities, both for the lack of attention to their rights in the field of rehabilitation and social services, in education - which have been abruptly interrupted for quarantines without alternative domestic care - and for their work in public and in private companies, where the protection of employees and workers with disabilities was compromised by several obstacles.

A positive element of the COVID-19 period was the attitude of prime minister Giuseppe Conte who, while maintaining political responsibility to the government on the issue of disability, met several times with the FISH and FAND federations⁴⁸ during the pandemic, including in the meeting “States Italian Generals”. In his communications to parliament, he reminded listeners that this segment of the population has also contributed to the development of legislation on protection measures aimed at persons with disabilities (unfortunately adopted sometime later) and that a disability expert from the Economic and Social Committee was part of the commission set up by the prime minister and coordinated by Vittorio Colao to elaborate proposals in phase two of COVID-19⁴⁹.

5. Some research on the effects of the pandemic on persons with disabilities worldwide

We still do not have an in-depth analysis of the number of research projects assessing the impact of the pandemic on persons with disabilities and their families around the world. However, it is enough to mention the statement by Dr. Hans Henri P. Kluge, WHO regional director for Europe⁵⁰ who stressed that in Europe “half of coronavirus deaths occurred in long-term care residences.

European Commissioner for Justice Helena Delli said that “persons with disabilities have borne a disproportionate burden compared to other European citizens”⁵¹.

The International Disability Alliance (IDA), the worldwide network that brings together the most important international and regional organizations of persons with disabilities, has conducted research on five continents to collect information and data to monitor how SARS-COVID-19 has affected the rights of the disabled. Various issues emerged from the investigation: lack of access to information and communications relating to COVID-19 for all persons with disabilities; barriers in accessing social protection measures and job protection (formal and informal, prevalent in countries seeking development, job losses, and barriers to the possibility of benefiting from remote work; lack of inclusion of the topic of disability in responses to COVID-19 by all levels of national and local government, with important communication breaks between national and territorial efforts. The report shows that most persons with disabilities worldwide have been negatively affected from the pandemic in one way or another, with old or new barriers, even in the reopening phase. Countries continue the management of COVID-19 as a public health policy issue, while in the following period, action should be taken to remove existing barriers and rebuild the healthcare system in a better way, starting with the most critical areas for improvement, in order to implement the development objectives for a sustainable future. Such an improved, sustainable system would include persons with disabilities as beneficiaries

of these improvements, in particular, access to education, employment, urban areas, and the collection of appropriate and disaggregated data, in order to apply the CRPD. IDA itself has testified with life stories of persons with disabilities collected around the world how the pandemic has affected the disabled⁵².

One of the significant findings of the global report on COVID-19 from the Disability Rights Monitor (2020)⁵³, in collaboration with IDDC⁵⁴, Disability Rights Fund⁵⁵ and Pretoria University⁵⁶, is that persons with disabilities were left behind, “regardless of their level of development across both wealthy and developing countries”.

The American Psychological Association conducted research that “shows persons with disabilities are at risk for mental health problems”⁵⁷. A disability-inclusive Covid response published by the House of Commons, in the UK, noted that the Office for National Statistics analysis estimated disabled persons made up 59% of all deaths involving COVID-19 from 2 March to 14 July 2020, in England and Wales⁵⁸. The UNICEF report on *Child Disability and Covid-19* (April 2020) stresses that “The greater burden faced by children living with disabilities means that additional efforts will be required to ensure their needs are being met when transitioning to the different pandemic phases”⁵⁹. The research of American Association on Health and Disability, that covers a broad spectrum of research areas, has conducted a specific research on *Novel Coronavirus Pandemic and Access to Health Services Among Adults with Disabilities Project*, showing where barriers, obstacles and discrimination intersect⁶⁰.

Various articles have been published in recent months on the topic of persons with disabilities during the pandemic, highlighting various critical issues: increase in the risk of poverty among persons with disabilities, the vulnerability of persons with cognitive disabilities (ID) as well as in the increase of physical, mental, and social effects of the pandemic⁶¹. In Italy, the scientific journal *New Secondary Research* published a special issue on COVID-19 and persons with disabilities in the area of education, highlighting the strong importance of inclusive education (Italy has the most inclusive education system in the world⁶²)

proposing some operational solutions⁶³. The UN Office of High Commissioner for Human Rights regularly collects research data on persons with disabilities and COVID-19 as these persons “face even greater inequalities in accessing healthcare during the pandemic due to inaccessible health information and environments, as well as selective medical guidelines and protocols that may magnify the discrimination persons with disabilities face in healthcare provision”⁶⁴. The UN also collects various research data and documents on disability and COVID-19⁶⁵.

6. Conclusions

Let us consider some final reflections. In times of crisis, atavistic stigmas resurface, as well as evaluations of those with socially undesirable qualities and the different way they should be treated. As long as persons with disabilities are considered invisible citizens or special, as long as they are not truly regarded as part of society and mainstream policies do not take care of them, they will always be subject to the risk of having their rights limited or ignored and will always be exposed, without justification, to different treatments, which violates human rights. The pandemic shows this situation in emergency actions, in medical triage, in lockdown of services, in general attention to respecting the rights and dignity of persons with disabilities. The visibility and highlighting of complaints and proposals is an essential moment in the work of associations and federations, as well as an opportunity to reflect on the policies addressed to them. The application of the *UN Convention on the Rights of Persons with Disabilities*, ratified by Italy, in 2009, and by 182 UN member countries, requires moving from a view of protective welfare, which treats persons with disabilities differently, often without justification, considering them vulnerable and fragile and segregating them, to a view of inclusive welfare, where they are full-fledged citizens able to participate and benefit on an equal basis with other citizens, in all policies and measures to protect them. In societies with disabled persons with negative, stigmatized characteristics (such as thoughtful persons of homosexual orientation, women in some Arab countries, or people with dark skin, ...), there

are also persons with functional limitations⁶⁶. The definition of disability in the CRPD is in fact a heuristic tool to understand how disability is a social creation: “Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.” It is easy to replace the characteristic “impairments” with other characteristics such as being a woman, being a migrant, belonging to religious and ethnic groups other than those prevalent in a country, having a homosexual orientation, etc. that in some societies create conditions of inequality.

The issue of segregating institutions and alternative solutions that violate human rights is an important bioethical issue. The reasons are many. A first strong reason derives from the fact that the *National Guarantor of the Rights of Persons Detained or Deprived of Personal Liberty*, an authority that intervenes to protect human rights, has once again recommended increasing controls to promote respect for human dignity. This increase shows that segregation of people into special and separate places, apart from society in general, can lead to human rights violations, to inhuman and degrading treatments, and that society should take steps to find alternative solutions, respectful of the quality of life⁶⁷ and adequate enough to maintain contact with the communities to which they belong. The second reason is that the social stigmas that affect persons with disabilities, and in recent years, also older persons, are unacceptable.

Such negative conceptions are supported by selected moral theorists and bioethicists that consider persons with disabilities sub-human⁶⁸ and expendable in the name of the good of the majority of the population, forgetting that all human lives experience some form of disability. Persons with disability must benefit equitably from the development of goods and services for all, as well as from general policies with appropriate support, even in emergency situations.

These negative views of disability run through all professions, an issue that derives from the inertia of prejudices still strongly present in populations around the world. It would be even more terrible, if such negative views guide doctors and health policies. However, bioethics

generally, as well as the *ars medica* and the law, has emerged to protect the weakest subjects of society, because every citizen is a precious asset for the state and every person, since “*all human beings are born free and equal in dignity and rights (...) without distinction of any kind such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status*”. These universal and inalienable principles enshrined in the Universal Declaration of Human Rights (ONU, 1948) cannot be violated by bioethics which has the obligation to promote, in its own expressions, the right to life, freedom, and security of every individual, in every situation, even in extraordinary ones such as a pandemic emergency.

Endnotes

- 1 Co-Director of the Center for Governmentality and Disability Studies (CeRC) “Robert Castel”, University “Suor Orsola Benincasa” of Naples (<https://www.unisob.na.it/ateneo/c007.htm?vr=1>), member of the Bioethics Committee of the Republic of San Marino and member of the World Council of Disabled Peoples’ International-DPI (www.dpi.org).
- 2 President of National Bioethics Committee of the Republic of San Marino and member of DH-BIO, Council of Europe, Professor of Bioethics at the Polytechnic University of Marche, Ancona (Italy).
- 3 <https://www.who.int/bulletin/volumes/89/7/11-088815/en/>.
- 4 See https://covid19.who.int/?gclid=CjwKCAiAi_D_BRApEiwASslbJ-bQSQc7MDJK3dFIURA6LuDJuIqeeCVGnwFJnjTcYb5kGOGdj6geZBoCITkQAvD_BwE.
- 5 See Pan American Health Organization. *Health response to the earthquake in Haiti, January 2010. Lessons to be learned for the next massive sudden-onset disaster*. 2011. <https://www.paho.org/disasters/dmdocuments/HealthResponseHaitiEarthq.pdf>
- 6 <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- 7 In the text of the CRPD, the States that have ratified the Convention are defined as “States Parties”.
- 8 The document comes from a European project on emergency in relation to persons with disabilities, and it was the first international reference on the issue. *Verona Charter on the Rescue of Persons with Disabilities in the Event of Disasters*: <https://internazionali.ulss20.verona.it/docs/projects/rdd/cartadiverona.pdf>
- 9 See the bibliography contained in MAECI-Development Cooperation, *Humanitarian Aid and Disabilities*. *Vademecum*, Rome, 2015.
- 10 Ibidem.
- 11 <https://www.unisdr.org/we/coordinate/sendai-framework>
- 12 <http://humanitariandisabilitycharter.org/>
- 13 *Interagency Standard Committee* is the United Nations’ main mechanism for coordination between humanitarian aid agencies. It is a single forum involving key partners from the United Nations and other governmental and civil society bodies. It was established in June 1992 on the basis of resolution 46/182 of the General Assembly. A representative of the Italian Disability and Development Network participated in the drafting of the guidelines.
- 14 <https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines>
- 15 Limiting losses meant that certain groups of people could be sacrificed (elderly, persons with chronic diseases, the seriously injured, etc.) while safeguarding the well-being of most other citizens.
- 16 The word “triage” is a French term that means “sorting, selection”: it is a system used to select people injured in accidents according to increasing urgency / emergency classes, based on the severity of the injuries reported and their clinical picture. Persons with disabilities involved in natural and human disasters are often not given priority assistance, even if they have not been injured, and because they are considered persons with impairment, they are rescued / assisted after the others.
- 17 For example, the organization responsible to assist the population in case of emergency situation does not include accessibility equipment for persons with disabilities (accessible bathrooms, usable routes, location of these persons close to collective services, provision of particular diets, etc.) and such actions are postponed to a later time. In reality, inclusive planning can easily provide for these services and equipment.

- 18 The multisectoral approach takes into account the various risk factors (health, social, economic, etc.), the different populations affected (men, women, types of families, the elderly, persons with disabilities, migrants, etc.) and the different solutions respectful of the various needs in terms of first aid, reception, reconstructions, etc.
- 19 *Towards more disaster resilient societies*: <https://edoc.coe.int/en/environment/6824-towards-more-disaster-resilient-societies-the-euro-pean-contribution.html>.
- 20 https://ec.europa.eu/echo/files/aid/countries/factsheets/thematic/consensus_en.pdf
- 21 https://www.consilium.europa.eu/register/en/content/out/?&typ=ENTRY&i=ADV&DOC_ID=ST-6450-2015-INIT
- 22 https://ec.europa.eu/echo/sites/echo-site/files/2019-01_disability_inclusion_guidance_note.pdf
- 23 <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=LEGISSUM%3Aem0047>
- 24 The welfare system linked to persons with disabilities is often organized in separate and “special” places (day centers, rehabilitation centers, long-term care institutions, ...) separated from society which makes the beneficiaries of those services invisible to society and to emergency services. See: *Disability rights during the pandemic A global report on findings of the COVID-19 Disability Rights Monitor 2020*, <https://www.internationaldisabilityalliance.org/covid-drm>.
- 25 See <https://opendatadpc.maps.arcgis.com/apps/opsdashboard/index.html#/b0c68bce2cce478eaac82fe38d4138b1>
- 26 <http://www.siaarti.it/SiteAssets/News/COVID19%20-%20documenti%20SIAARTI/SIAARTI%20-%20Covid-19%20-%20Clinical%20Ethics%20Reccomendations.pdf>
- 27 In a 2013 general audience, Pope Francis made explicit his criticism of the ‘throwaway culture’: “We are experiencing a moment of crisis; we see it in the environment, but above all we see it in man. The human person today is in danger; there is the urgency of human ecology! What commands [respect] today is not human beings; it is money. If a man dies of cold or starvation, it is not news, but if the stock exchange falls by ten points, it is a tragedy! So people are discarded, as if they were waste. This “throwaway culture” tends to become a common mentality, which infects everyone. Human life is no longer seen as a primary value to be respected and protected, especially if they are poor or disabled, if they are not yet needed - like the unborn child - or no longer needed - like the elderly. See <https://www.papafrancesco.net/la-cultura-dello-scarto-le-persone-trattate-come-dei-rifiuti/>. A. Mariani, *Papa Francesco: no alla “cultura dello scarto (Pope Francis: no to the “throwaway culture”*), IF Press, 2015.
- 28 <http://www.sanita.sm/on-line/home/bioetica/comitato-sammarinese-di-bioetica/documents-in-english.html>
- 29 <https://en.unesco.org/themes/ethics-science-and-technology/bioethics-and-human-rights>
- 30 According to Eurostat (EU-SILC 2018), there are about 87 million people with disabilities (aged 16 and over) living in private households in the European Union. These data do not include persons living in long-term care facilities (about 1,100,000) and persons with disabilities below 16 years old (about 3,000,000). <https://ec.europa.eu/eurostat/web/income-and-living-conditions/publications>
- 31 European Disability Forum, *Open Letter to Leaders at the EU and in EU Countries: Covid-19 – Disability Inclusive Response* (<http://www.edf-feph.org/newsroom/news/open-letter-leaders-eu-and-eu-countries-covid-19-disability-inclusive-response>) and other initiatives available at: <http://www.edf-feph.org/>
- 32 UNESCO - International Bioethics Committee and World Commission on the Ethics of Scientific Knowledge and Technology, *Statement on Covid-19: Ethical Considerations from a Global Perspective*: <https://unesdoc.unesco.org/ark:/48223/pf0000373115>
- 33 European Group on Ethics in Science and New Technologies, *Statement on European Solidarity and the Protection of Fundamental Rights in the COVID-19 Pandemic*: https://ec.europa.eu/info/sites/info/files/research_and_innovation/ege/ec_rtd_ege-statement-covid-19.pdf
- 34 DH-BIO, *DH-BIO Statement on human rights considerations relevant to the COVID-19 pandemic*: <https://www.coe.int/en/web/bioethics/covid-19>
- 35 <https://www.who.int/ethics/topics/outbreaks-emergencies/covid-19/en/>
- 36 E. g., Catalonia (<https://www.redaccionmedica.com/contenido/images/recomanacions-suport-decisions-let.pdf.pdf.pdf.pdf.pdf.pdf>)
- 37 E. g., Alabama (<https://mh.alabama.gov/covid-19-dd/>), Maryland (<https://www.mhamd.org/>)

- coronavirus/get-help-now/living-with-mental-illness-during-covid-19-outbreak/), Pennsylvania (<https://www.inquirer.com/health/coronavirus/>), Tennessee (<https://www.curesma.org/wp-content/uploads/2020/03/Cure-SMA-Tennessee-Medicaid.pdf>).
- 38 See the articles (in Italian language) reporting the debate between the SIAARTI and the National Federation of Orders of Surgeons and Dentists (FNOMCeO) on the topic <https://portale.fnomceo.it/anelli-fnomceo-su-documento-siaarti-nostra-guida-resta-il-codice-deontologico/> and https://www.quotidianosanita.it/lavoro-e-professionisti/articolo.php?articolo_id=85358
- 39 In this period, the number of infected persons reached an average of 4,000 to 5,000 per day. ICU facilities were running out of beds, and the number of deaths increased, reaching 600 to 800 deaths daily. For example, review newspaper reports during March and early April: <https://www.ilsole24ore.com/art/coronavirus-italia-news-ultime-notizie-aggiornamenti-10-aprile-ADxcpYJ>, https://www.repubblica.it/cronaca/2020/03/30/news/coronavirus_bilancio_morti_guariti_positivi_100mila-252710050/.
- 40 In Italy, the responsibility of long-term care lies with the 20 regions within Italy, which often define the typology of these services differently. These services, financed by social, socio-health, and health funds, often created administrative confusion, which made assessment difficult. The most common abbreviations in the regions are the RSA (Assisted Health Residences, which mainly host non-self-sufficient elderly persons) and RSD (health residences for persons with disabilities, which house persons with disabilities aged 18 and over). The ISS investigation analyzed RSAs only while the preparation of a survey on RSD is currently underway.
- 41 <https://www.epicentro.iss.it/en/coronavirus/sars-cov-2-survey-rsa>
- 42 Actually, this information is more precise, as the WHO states: “The incubation period of COVID-19, which is the time between exposure to the virus and symptom onset, is on average 5-6 days, but can be as long as 14 days” see <https://www.who.int/news-room/commentaries/detail/transmission-of-sars-cov-2-implications-for-infection-prevention-precautions>.
- 43 The Italian Disability Forum, an Italian member of the European Disability Forum, continuing its meritorious work of alternative reporting to the UN Conventions ratified by Italy, denounced the cruel, inhuman and degrading treatment to which persons with disabilities were subjected during the SARS-COV19 in Italy, presenting an alternative report to the UN Committee of the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment) which this year examined the official Italian report. See the web site of the UN High Commissioner on Human Rights https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Countries.aspx?CountryCode=ITA&Lang=EN.
- 44 See https://www.adnkronos.com/salute/sanita/2020/10/20/covid-allarme-nelle-rsa-mancano-medici-infermieri_x79021dpeT5xMwkaF9qdVN.html.
- 45 There are hundreds of complaints filed by family members of persons who died in nursing homes due to COVID-19. The complaints ask to investigate the lack of protection systems whose absence has allowed the massive spread of the coronavirus in these places and the consequent deaths of their relatives. See as example <https://www.ilgiorno.it/morti-rsa-1.5188910> and <https://www.lastampa.it/torino/2020/04/21/news/troppi-anziani-morti-nelle-rsa-per-il-coronavirus-prime-denunce-da-parte-dei-parenti-1.38745162>.
- 46 See Guarantor Announcements, in particular, that of 12 March 2020: <http://www.garantenazionaleprivatiliberta.it/gnpl/>.
- 47 Five deaths and 162 infections among doctors, nurses, assistants and patients were recorded in the scientific research and treatment institute (IRCCS) ‘Oasi Maria Santissima’ in Troina, Sicily, residence for the mentally disabled. The Region has sent an emergency commissioner to the facility, and nurses and doctors from the Army and Navy have been deployed. See the following articles. https://www.ansa.it/sicilia/notizie/2020/04/01/oasi-troina-morta-ospite-112-positivi_8427ba29-06ee-4cdc-a415-1cbe9f2fa322.html and https://palermo.repubblica.it/cronaca/2020/04/14/news/coronavirus_focolaio_all_oasi_di_troina_la_procura_indaga_per_omicidio_ed_epidemia_colposi-253991754/.
- 48 The Italian Federation for Overcoming Handicap (FISH, www.fishonlus.it) and the Federation of the National Association on Disability (FAND, www.fandnazionale.it) are the main representative organizations in Italy that represent the majority of the association of persons with disabilities and

- their families.
- 49 Appointed by the DPCM (Decree of the Presidency of the Council of Ministers) on April, 10 2020.
- 50 See web site <https://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-covid-19/statements/statement-invest-in-the-overlooked-and-unsung-build-sustainable-people-centred-long-term-care-in-the-wake-of-covid-19> .
- 51 See https://ec.europa.eu/commission/commissioners/2019-2024/dalli/announcements/speech-commissioner-dalli-impact-coronavirus-outbreak-persons-disabilities_en .
- 52 See web site <http://www.internationaldisabilityalliance.org/covid-drm> .
- 53 See note 18. “The report sets out the outcomes of a rapid human rights-based global monitoring initiative – the COVID-19 Disability Rights Monitor (COVID-DRM) – sponsored by a consortium of seven leading disability rights organizations, which took place between 20 April and 8 August this year [2020], including the testimonies of 2,152 respondents from 134 countries, predominantly from persons with disabilities themselves. The report draws the worrying conclusion that states have overwhelmingly failed to take sufficient measures to protect the rights of persons with disabilities in their responses to the pandemic”. The EU has the majority of responses, from Western Europe (515) and Southern Europe (330).
- 54 See web site of International Disability and Development Consortium, <https://www.iddcconsortium.net/> . The IDDC has conducted research in developing Countries on pandemics and disability.
- 55 See <https://disabilityrightsfund.org/> .
- 56 See <https://www.up.ac.za/> .
- 57 Details of the research and bibliography are available on web site <https://www.apa.org/topics/covid-19/research-disabilities> .
- 58 See <https://researchbriefings.files.parliament.uk/documents/CDP-2020-0101/CDP-2020-0101.pdf> .
- 59 See <https://data.unicef.org/topic/child-disability/covid-19/> .
- 60 See <https://aahd.us/dissemination/covid-19-disability-survey/> .
- 61 K. Courtenay, B. Perera, *COVID-19 and people with intellectual disability: impacts of a pandemic*, pp. 23-236, in *Irish Journal of Psychological Medicine*, vol. 37, issue 3, September 2020, Special issue. COVID-19 perspectives, <https://www.cambridge.org/core/journals/irish-journal-of-psychological-medicine/article/covid19-and-people-with-intellectual-disability-impacts-of-a-pandemic/EE2156045429D885B49CBBBEBA5A96C5> .
- 62 See the data of the educational year 2016-17 from the European agency on special need and inclusive education that report that the 99,2% of pupil with disabilities in Italy studies in ordinary classes, <https://www.european-agency.org/>.
- 63 *Nuova Secondaria Ricerca. Mensile di cultura, ricerca pedagogica e orientamenti didattici*, n° 2, ottobre 2020, *Dossier I, La scuola durante e dopo il COVID*, ed. Studium, Brescia, <http://www.edizionistudium.it/riviste/categorie/Nuova%20Secondaria%20Ricerca> .
- 64 See https://www.ohchr.org/Documents/Issues/Disability/COVID-19_and_The_Rights_of_Persons_with_Disabilities.pdf .
- 65 See <https://www.un.org/development/desa/disabilities/covid-19.html> .
- 66 Remember the definition of disability in the preamble) of the CRPD: “*disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others*”; if you replace the term “impairment” with features such as skin color, homosexual orientation, female gender, ... it is understood how society can impede those people in carrying out activities and accessing the rights.
- 67 The quality of life of persons with disabilities depends on enjoying equal opportunity and access to rights and benefits of a society that continually strives to support and overcome barriers and discrimination, as well as helping to foster a more positive perception of concerned persons, see C. Francescutti, *Disability and Happiness* p.251-266 in *Minority Reports* n. 6, January-June 2018, *Participation and Innovation*, see <http://mimesisedizioni.it/riviste/minority-reports/minority-reports-06.html> .
- 68 Among these, the most representative philosopher is Peter Singer. Singer’s approach (P. Singer, *Practical Ethics*. Cambridge University Press; P. Singer, *Should the Baby Live?* Oxford University Press, 1985) is similar to that of the Nazis who considered certain categories of persons (persons with disabilities, Jews, mentally ill, Roma and Sinti, etc.) unneeded, considering them useless lives. The difference is that the Nazis were motivated by the purity of the race (but not only)

and Singer by the use of resources for the good of the majority of the population. However, these approaches violate the substance of the human rights paradigm - a global paradigm after the Universal Declaration of Human Rights (1948) - which underscores that from the moment of birth, every human being, regardless of his or her characteristics, enjoys all human rights: "All human beings are born free and equal in dignity and rights "...

* Websites accessed on 10 January 2021.